DOCUMENT RESUME

ED 197 083 CE 027 614

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| TITLE | Proceedings of the Annual Conference: Rehabilitation Research and Training Centers of the National Institute of Handicapped Research. Meeting the Opportunities of the National Institute of Handicapped Research (4th, Washington, D.C., May 5-7, 1980). Special Edition. |
| INSTITUTION | Arkansas Univ., Fayetteville. Arkansas Rehabilitation Research and Training Center.; National Inst. of Handicapped Research (ED), Washington, D.C. |
| PUB DATE | Sep 80 |
| NOTE | 66p.: Photographs will not reproduce well. |
| JOURNAL CIT | Informer: v9 n3 Sep 1980 |
| EDRS PRICE | MF01/PC03 Plus Postage. |
| DESCRIPTORS | Developmental Disabilities: *Disabilities: Diseases: *Federal Programs: Futures (of Society): Hearing Impairments: Injuries: *Long Range Planning: Mental Disorders: Mental Retardation: Physical Disabilities: Public Policy: *Rehabilitation: Rehabilitation Centers: *Research: Research Projects: Research Utilization: Visual Impairments: Vocational Education |
| IDENTIFIERS | *National Institute of Handicapped Research: *Rehabilitation Research and Training Centers |

ABSTRACT

Keynoted by Dr. Margaret J. Giannini, Director of the National Institute of Handicapped Research (NIHR), these conference proceedings focus on present concerns and future issues facing the NIHR and researchers and trainers in the field of rehabilitation of the handicapped. In her address, Dr. Giannini outlines priorities for the NIHR for the next five years, such as training personnel engaged in rehabilitation activities, expanding core research programs, and putting the results of research projects to work. In greetings from the U.S. Department of Education and Rehabilitation Services Administration, respectively, Edwin W. Martin and Robert R. Humphrey point out the need for researchers and trainers to work together with their departments to improve delivery of services to the handicapped. In another major address, Joseph Fenton details what is happening in Rehabilitation Training Centers (RTCs) around the country and suggests directions for the future. RTC input into the NIHR long-range plan is then given in the following research areas: medical, blindness, vocational, mental retardation, mental health, and deafness; other NIHR long-range planning discussed includes the following: overview of the planning process and plans; management projects, medical projects, dissemination and utilization, psychosocial projects, and international programs. A legislative update, conference evaluation, and a list of conference participants, along with group meeting reports, are also included in this document. (KC)

ISSN 0194-2336
INFORMER
National Institute of Handicapped Research
Washington, DC 20201 Vol. 9, No. 3 Sept. 1980

Special Edition:

# Proceedings of the Fourth Annual Conference

## of the National Institute of Handicapped Research

Rehabilitation Research and Training Centers

**In cooperation with the National Association of Rehabilitation Research and Training Centers**

Washington, DC
May 5-7, 1980

ED197083

OE 027614

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

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**INFORMER**
Volume 9, No. 3
September 1980

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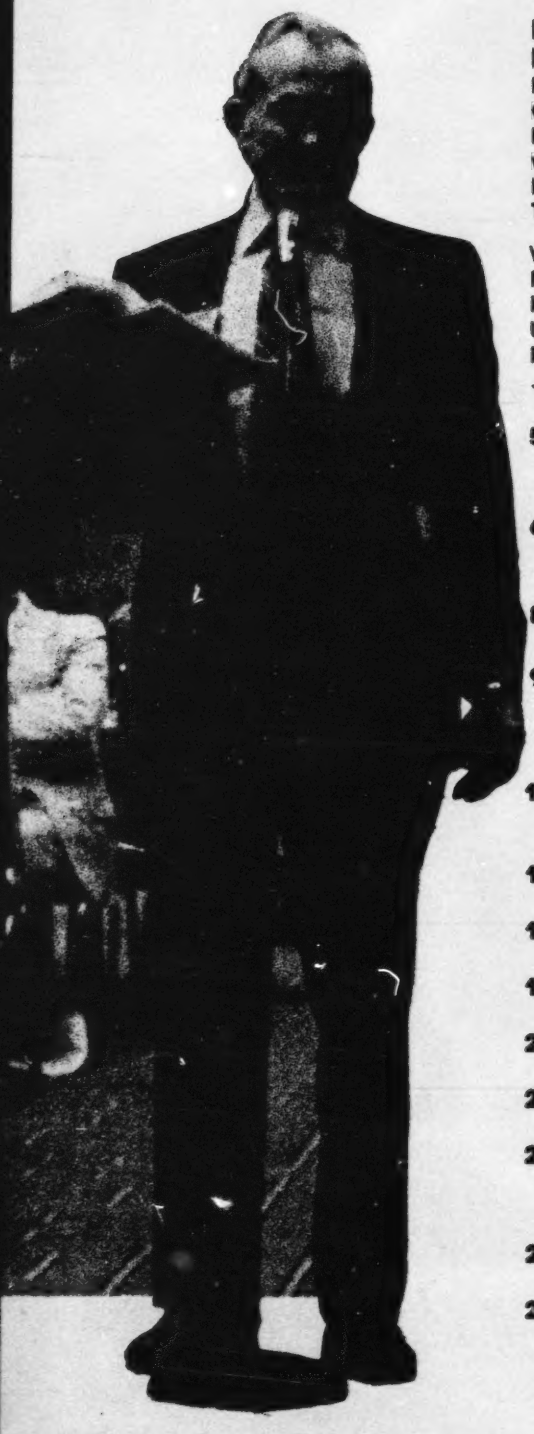

**Proceedings of the Fourth Annual Conference**
**Rehabilitation Research and Training Centers of the National Institute of Handicapped Research in cooperation with the National Association of Rehabilitation Research and Training Centers**

Washington, DC
May 5-7, 1980
Hosted by The George Washington University Medical Rehabilitation Research and Training Center

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ISSN 0195-2358

These proceedings were prepared by the University of Arkansas Rehabilitation Research and Training Center in cooperation with The George Washington University Research and Training Center.

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Photography by Mary C. Gunzburg and David L. Sigman.

**INFORMER** (USPS 495-010) is published quarterly by the Arkansas Rehabilitation Research and Training Center, University of Arkansas, Fayetteville, Arkansas, in cooperation with the Arkansas Rehabilitation Services. Controlled circulation postage is paid through official permit, Washington, DC.

**Postmaster:** Send address changes to **INFORMER,** Information Exchange Program, Arkansas Rehabilitation Research and Training Center, P.O. Box 1358, Hot Springs, Arkansas 71901.

All programs administered by the University of Arkansas are rendered on a nondiscriminatory basis without regard to handicap, race, creed, color, sex, or national origin in compliance with the Rehabilitation Act of 1973 and Title VI of the Civil Rights Act of 1964.

## Welcome

**Irene G. Tamagna, M.D.**
**Conference Chairperson**
**Project Director**
**The George Washington University**
**Medical R&T Center**

I would like to welcome you to beautiful Washington, DC on this nice spring day, and to the Fourth Annual Conference of the Rehabilitation Research and Training Centers of the National Institute of Handicapped Research and the National Association of Rehabilitation Research and Training Centers. As you know, we had very short notice to arrange this meeting, which was made possible with the help of our Program Planning Committee, Dr. Don Dew, our Training Director, and Mrs. Pat Alexander, our Administrator. Without their special efforts, we could not have gotten this meeting together. We do hope that you will find the hotel and meeting arrangements satisfactory. This hotel is wheelchair accessible, and interpreter services will be provided throughout the meeting.

This is a very important meeting to all of us. It is our first meeting under the National Institute of Handicapped Research, and we are very happy to have Dr. Margaret Giannini, Director of the Institute, with us today. Dr. Ed Martin, newly-designated Assistant Secretary for Special Education and Rehabilitative Services, will also come and talk to us.

The RT-9 Center at The George Washington University is especially honored to have been selected as the host center for this important meeting; therefore, I have asked our Provost and Vice-President for Academic Affairs, Dr. Harold Bright, to bring you greetings from The George Washington University.

**Dr. Harold F. Bright**
**Provost and Vice President**
**for Academic Affairs**
**The George Washington University**
**Washington, DC**

It is often very difficult to say anything original when one is asked to bring "greetings," but I would like you to know that I have a very special interest in this group because my wife is a paraplegic and Dr. Tamagna has been taking care of her for a long time.

You all know you are very welcome and we are happy to have you at this meeting. I hope you enjoy your stay in Washington and that this meeting will be very fruitful for you.

**Joseph B. Moriarty, Ph.D.**
**President, NARRTC**
**Project Director**
**West Virginia University**
**Vocational R&T Center**

It is always a great treat to see old friends and to reestablish acquaintances. It is of course good to see folks that we have worked with in the R&T Center Program. I would like to take this opportunity to note and to appreciate the fact that we continue to see old friends that are part of the R&T extended family. I note here, our Advisory Committee people, including consumers on those committees. I also note RSA Central Office and Regional Office staff, and also representatives from Regional Rehabilitation Institutes and Regional Continuing Educational Programs. It is good to have you continue to serve with us as part of what we conceive to be a very rich, and hopefully within NIHR, a more energetic family.

Without further ado I would like to proceed with the very pleasurable task of introducing our keynote speaker. It is a great honor for me to present to you Dr. Margaret Giannini, Director of the National Institute of Handicapped Research.

*Dr. Moriarty concluded his welcome introduction with an overview of Dr. Giannini's background and contributions to rehabilitation which is summarized on the following page.*

**OPPOSITE PAGE: (left to right) Irene G. Tamagna, M.D., Conference Chairperson, and Margaret J. Giannini, M.D., Director, National Institute of Handicapped Research, Washington, DC.**

# NIHR
# The Next Five Years

**Margaret J. Giannini, M.D., Director**
**National Institute of Handicapped Research**
**Washington, DC**

*Dr. Giannini is founder and former director of the Mental Retardation Institute of New York Medical College and a past president of the American Association of University Affiliated Programs and the American Association on Mental Deficiency. She has been actively involved with the National Committee on Children with Handicaps of the American Academy of Pediatrics and the International Activities and Prevention Committees of the American Association on Mental Deficiency; has served as consultant to the Mental Retardation Construction Unit of the National Institute of Health and to the President's Committee on Mental Retardation; has been an advisor on MR/DD to the UN Department of World Technical Cooperation; and is a member of the International Health Society and past director of its developmental disabilities program.*

*Dr. Giannini has headed the efforts of numerous state, local, and community development organizations including the New York State Association for Retarded Children; State Council for Developmental Disabilities; Honorary Committee of the New York State Special Olympics; and the Mental Retardation Task Force of the New York State Education Department. She has served on Governor Rockefeller's Committee on Children of the New York State Department of Mental Hygiene. Dr. Giannini is the recipient of the Bronze Medal of the American Academy of Pediatrics, the Enrico Fermi Education Award, the Wyeth Medical Achievement Award and the Key to the City of Bologna, Italy.*

I am really very pleased to be here today and to open your fourth national meeting. I feel very privileged to address you as the first Director of the National Institute of Handicapped Research. I know a number of you already; we have had occasions to speak and to get acquainted, and I hope that I will get to know the rest of you on a one-to-one basis within the very near future.

When I was asked to speak here today I thought to myself, "What would this group really like to hear, and what do they want to learn in terms of the Institute?" What I would like to do initially is set the tone of this meeting and, perhaps, for the future. I think all of us today are really futurists, and when we talk about the future something happens—two types of attitudes seem to surface very quickly. On the one hand we have the optimist, who has hopes, dreams and visions and endorses the idea that somehow those will become a reality with whatever efforts are required. On the other hand we have the pessimist, who looks at the world as if it is in an imminent state of collapse with a dismal future. The pessimist is full of despair and feels that very little is going to happen. I happen to think that we are the futurists of the former type and not the latter. I would also like to indicate that this is the tone of most of the rehabilitation professionals, interest groups and consumers around the country which I have had the opportunity to meet and speak with so far.

Let me tell you a little bit in terms of what the National Institute of Handicapped Research foresees for the future. I am very pleased to report to you that we do have a Plan. Many of you were very actively involved in that Plan, for which I publicly thank you. In fact, there was a great deal of input into the Plan: we sent out approximately 3,000 letters to various professional and interest groups for information. Many of you probably saw the letter which contained some very specific questions, goals and objectives on which we needed feedback. And we did get a great deal of good response from various interest groups and professionals and also from the most important segment—handicapped consumers.

So I think that we have a very good Plan. It is not written in stone. It is not the final word. We certainly can alter it, modify it each year as we all participate together and as options and alternatives are decided, evaluated and set. But I think that at this point in time, with the limited amount of resources that we have inhouse, it is a good instrument and that you will be pleased when you see it.

We will not be ready to deliver the Plan to the Congress on May 6 because of the delay when we were in-between department Secretaries. However, with Dr. Martin officially designated as Assistant Secretary of the Department of Education the process should go more quickly.

If you have not heard already, you will be excited to know that the President did announce the National Council on the Handicapped last Thursday during the meeting of The President's Committee on Employment of the Handicapped. President Carter also stated that by Executive Order the National Institute of Handicapped Research is **the** Institute where all research affairs concerning handicapped persons will be housed and the focal point where all the decisions, research priorities and inter-relationships that must take place will be consolidated. I think that is a tremendous statement for the President of the United States to make publicly, because, even though it happened by legislation, this officially states that the United States has now gone "on record" as officially committed to handicapped individuals. That is a bright light when we are talking about futures! He said, too, that one of his primary initiatives will be on independent living, and, of course, that concerns us a great deal. I was very pleased with the President's statement. I was not warned ahead of time what he was going to say, being pleasantly surprised as many of you were.

Now, let me talk a little bit about the contents of the Plan. By now many of you have received information on some of the initial directions that I hope the Institute will take to strengthen, expand, and to be more creative and innovative in terms of the R&T Centers. And I hope that the objectives and goals in terms of this year's directions, particularly as they involve R&T Centers, meet with your approval. I did take the opportunity to discuss this plan with a number of you before I finalized it, and I had a feeling that many of you agreed that this would be the most objective and the fairest way to start. I hope you continue to think this way because it would be very meaningful in terms of our strength, our building, and what we are going to do in concert.

You know the broad mandate of the

legislation. In its broadness it encompasses the full spectrum of research activities of all handicapped persons whatever their disability, their ages or their unmet needs. And I think that we can be very instrumental in changing the world for handicapped individuals. We have said this so many times with lofty rhetoric, with lots of discussion, with lots of planning, but we really have not been able to translate that into a product or a commodity—into the ideal service delivery models for handicapped individuals. I know that you are sensitive to the community of handicapped individuals, to their uneasiness, their impatience, their appeal to do something. I hope that we can do some of these things. It's time for a change! This is the moment! However, we have to, on the one hand, instigate change for good things to happen. But we also must be prudent that with change must come patience, because a certain amount of accommodation must take place in all change.

So I am hopeful that with our mandate, and specifically with the Research and Training Center Program, we will be able to provide the programs of rehabilitation research to train personnel engaged in rehabilitation activities so that the needs of handicapped individuals in geographic areas served by the Centers are taken into account in program activities. Aspects of research such as applied, basic, medical rehabilitation research; research on psychological and social aspects of rehabilitation; research into vocational rehabilitation and research on blindness and deafness are all conducted by these Centers. I would hope, too, that with these kinds of goals and objectives in mind, we will be able to expand your core research programs with the new initiatives that we must address ourselves to within the legislation. This is a golden opportunity for all Centers to expand responsibilities and augment ongoing projects, for there is a need to fortify and to expand Research and Training Centers. There is a need to become more creative and innovative in our research and demonstration projects and to think more in terms of utilization and how we can best serve handicapped individuals with our models of utilization and dissemination activities.

Within those priorities we will, of course, become involved in the many areas of prevention, restorative management, and maintenance management. What are these optional models and which are the best to demonstrate and transfer throughout the country? We will also address ourselves to all the problems concerning handicapped individuals in terms of models—housing, transportation, employment, the employer. How can we better make a marriage with industry so that we can get into marketing? We have done some wonderful things with industry. We have enchanted them to demonstrate some very unique devices, especially in technology, that are very meaningful to handicapped individuals. We never seem to get to the marketing, and that aspect needs a great deal of attention and effort. We are going to try to coordinate bench research and applied research into the final model of service delivery. We will attempt to delve into any area that is innovative, that is creative, that really is meaningful to handicapped persons.

I also want to emphasize the importance of our international segment to the National Institute of Handicapped Research. This gives us a wonderful opportunity to continue to exchange information with our foreign colleagues, to initiate creative research which in many cases can go much more swiftly in foreign countries than in this country, and also to act as foreign diplomats and ambassadors of the United States Government. This is a very significant relationship when we get to the common denominator of serving handicapped persons. It is almost akin to the musical world. Musicians immediately have a rapport with each other . . . they seem to belong on the same wavelength without discrepancies and obstacles to communication. They understand each other. And I think that in many ways those of us in the handicapped world instinctively understand each other. We have a few rough edges, but I think we can overcome these. The time has come when we must speak with one voice. We have spoken well with many voices, but we have not totally synchronized and therefore the melody does not come out as perfect music. We must be productive together; we no longer have the luxury of time. The handicapped community is impatient, and rightfully so. We know a great deal, but there is a lot of information that we must "put together." We have had a lot of good research done by many of you, who are really the leaders. You are the people who are the constituency which can represent us and create the service delivery models that we are aching for in this country. And then we must become the leaders for the world because the United States is still the focal point to which everyone looks.

Let me also say that many of the priorities that you will be receiving very shortly as a follow-up to my earlier correspondence are following many of the mandates in a "stretched way," to do so much with so little. I must be very prudent, however, and I hope that you will be generous with your thoughts in terms of how the Institute is trying to get off the ground. It is difficult. We have many arenas into which we must enter not only to build bridges but to mend bridges as well. And with that, to also spread the message that the Institute is the place where handicapped research is going to be meaningful and really serve our country's handicapped individuals. So when you have differences of thought, remember, I am only a telephone away. I am not inaccessible. You can share your anxieties, your questions, your incomplete information, and your half-sentences, which I find are very common. The best way to get information is to go to the source, and I'll be glad to answer your questions if they are not resolved elsewhere to your satisfaction.

I hope that now I have set the stage, that from now on, as I stated in talking about the future, we will continue to talk together, to think together, to disagree with each other, to agree with each other, to compromise, but we will do it together. This is the only way that this Institute will be meaningful, not only in terms of your goals, your commitments, and your aspirations, but to the community which we serve—handicapped individuals. That is what it is all about! We need each other and from now on we must talk as "we" and no longer "you" and "me." We are going to make this an Institute that will be not only of academic excellence, but hopefully one which will be productive and meaningful, proof that it was worthwhile to create this National Institute of Handicapped Research.

## Special Greetings

**Edwin W. Martin, Ph.D.**
**Assistant Secretary for Special Education and Rehabilitative Services**
**Department of Education**
**Washington, DC**

*Dr. Edwin Martin was confirmed by the Senate on June 18 (shortly after this conference) as the first Assistant Secretary for the Office of Special Education and Rehabilitative Services in the new Department of Education. Dr. Martin has served as past Director of the Bureau of Education for the Handicapped, as Deputy Commissioner of Education, and has received awards from many organizations serving handicapped persons, including the National Easter Seal Society, the United Cerebral Palsy Association, the Association for Children with Learning Disabilities, the American Speech and Hearing Association, the National Association of State Directors of Special Education, and the Association for Retarded Citizens. In 1970 he was awarded the Superior Service Award from HEW for "visionary leadership in developing, broadening, and implementing a federal commitment to the special education needs of handicapped children" and in 1974 received the Honorary Doctorate of Humane Letters from Emerson College at Boston for his leadership on behalf of the civil rights of handicapped persons.*

It is a great pleasure for me to be with you on this important and symbolic day, the first day of the Department of Education's formal existence. I think it speaks well for the timing of our intersecting interests that we could meet on such an occasion, and I look forward to continuing exciting interactions with you.

The new Assistant Secretariat for Special Education and Rehabilitative Services has, as I see it, four major components—RSA, NIHR, the Council, and the Office of Special Education. As Public Law 94-142 has grown, some have tended to overlook the research, training and other discretionary activities carried out in behalf of education for the handicapped. In the Office of Management and Budget and in the Congress itself, the question has been asked, "Well, now that we have all of this service money, shouldn't we just drop the programs that were designed for such purposes as developing new models for early childhood education and new models for dealing with the severely handicapped? Shouldn't we allow the states to use their own money to do training and perhaps an innovative activity instead of funding such enterprises under the Education of the Handicapped Act?"

Personally, I cannot think of anything that would be more short-sighted, anything that would be less in the interest of the public, than to cut the service delivery programs off from the sources of innovation and development. And so far we have been successful in not only heading off reductions in this area but in maintaining a modest growth. It is difficult. The budgets have been tight. There is a natural tendency for available dollars to be vacuumed up into the service delivery programs and one can, in fact, argue that those are legitimate priorities. But instincts developed in the years that I have been in government impel me toward continued balanced growth in program development, training, innovation and model development, dissemination, technology development, and service delivery to people. I look forward to continuing that.

Focusing on the first of the four components I mentioned, the idea of having a National Institute of Handicapped Research has been a dream that many people have shared over the years—the hope of putting together increased resources, more highly developed and trained staff, and a closer working relationship with the research community across a whole broad range of disability from infants through the elderly. It is an exciting idea, and I intend to work with all of you in every way possible to bring that idea to its quickest possible fruition. The other day Fred Fay used the phrase that "the R&T Centers are the building blocks of the Institute," and I thought that was an interesting concept. I look forward to seeing these building blocks being put into place with the cement necessary to give them a firm foundation for the rest of our work.

There are a lot of areas where the programs in education and the programs in rehabilitation can mutually reinforce each other, resonate with each other, and amplify the thrust. Peg (Dr. Giannini) and I have already talked briefly about how we can tie together the early childhood end of our activities. The mission of the Institute is one in which we have a major priority on the special education side. Many of you know that over the years we have funded literally hundreds of model pre-school programs in the 0-3 age range, plus other programs in research centers that deal with rehabilitation as well as several other programs tying together R&T Centers and University Affiliated Centers, as well as programs in schools and private facilities. We also have begun a series of research institutes in the early childhood area. I can look forward to your meetings in the future as we attempt to further increase the communication between the research institutes dealing with children's education and learning problems, and also centers where we have been focusing on the nature and development of learning disabilities.

We have had an intersection between the various programs that have been part of the Education of the Handicapped Act that I hope will continue and be amplified through collaborative work with the Rehabilitation Services Administration and with NIHR. Perhaps a classical example was the research that was done some years ago indicating that the use of residual vision was not being exploited in most educational programs for blind and visually handicapped people. That research was well known and recognized in the research community but was having almost no impact on the training community. So we put together a series of training institutes and sessions which eventually were available to every teacher of the visually handicapped in the United States.

## Greetings from RSA

Not all took part, but over a period of time a tremendous number did so. I am sure that this undertaking played a role in the marked increase that has taken place in the use of low vision or residual vision in educating handicapped children.

Similarly, in some of the work done in supporting the Optacon, we have again taken early research findings and moved them into our media and dissemination program, where our training program then picked up the technology, as it did in the low vision projects, and conducted training institutions across the country to train teachers to use the Optacon with children. For several years we have been spending about $1 million a year purchasing Optacons and training people to use them. It is this kind of research-to-development-to-dissemination and marketing-to-teacher education-to-service continuum that we should strive for, not just within the rehabilitation and research programs, but wherever it is possible to integrate activities across the total range of disabled persons, from infancy through the elderly. I look forward to that, and I think that many activities can be brought together. I see that as a major mission of mine. I think that is what the Congress intended in bringing the Institute together with the Rehabilitation and Special Education organizations, and I think it is the most exciting part of the whole enterprise. The opportunity to work together and to understand each other's goals and priorities, to come together around a common search for knowledge and a common implementation strategy, will be the real prospect for the future, and I think we will make progress toward it.

I look forward to working with Peg (Dr. Giannini), to supporting her, and to working with you and getting to know you better. I hope it will be possible for me, even though we do not expect to do a lot of traveling, to stop and visit the R&T Centers and get a sense of what you are doing firsthand. I look forward to getting better acquainted and to hearing from you as to what the priorities should be, not just for research but for the total development of programs in the Assistant Secretariat.

*A question and answer period followed the addresses given by Director Giannini and Assistant Secretary Martin. This material appears on pages 10 and 11.*

**Robert R. Humphreys**
**Commissioner**
**Rehabilitation Services Administration**
**Washington, DC**

*Robert Humphreys was sworn in on November 7, 1977 as the fourth Commissioner of the Rehabilitation Services Administration and served in that post until June 1980, approximately one month after this conference.*

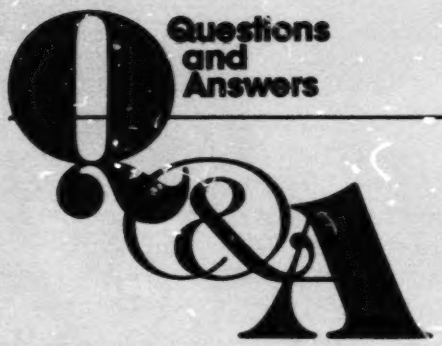
It's very good to be here with you. I did not mean to preempt your program at all; I just stopped by as an interested observer to see your progress and see all the things that the R&T Centers are doing together.

Your Association has come a long way in a short time and the interchange that has been going on in the meetings that I have observed is absolutely excellent. That has been a tradition with those of you who have had close relationships with us in the Federal sector in times past, and I am glad to see it continuing.

Let me say for my own part, and speaking for the agency I represent, that I concur wholeheartedly with what has been said in terms of the need for a very close continuing relationship between research and engineering technology and utilization activities, as manifested through the Research and Training Centers and other research components of the National Institute of Handicapped Research, and the service delivery system. Just because we are now two separate agencies does not suggest to me that we should go our separate ways . . . quite the contrary insofar as the legislative intent is concerned. I am a member of the Director's Interagency Committee on Handicapped Research and we are, by statute, also to participate in the Long-Range Plan for the Institute. But beyond that it is vitally important that as soon as the Institute has an opportunity to develop as an entity, and it is progressing toward that end, that RSA and the Institute have a strong liaison with each other and interact constantly in order to insure the greatest possible results for the people we serve, the disabled people of this country.

Likewise, it is of equal and critical importance that the Research and Training Centers maintain their close affiliation with the state rehabilitation system. If you do not know what the service delivery problems and needs are, you cannot attach relevance to what each of you respectively is doing, and then we have a bifurcated system that really has not reached and cannot reach its maximum potential.

So if I leave one message with you it is that I intend to strengthen our alliance for the benefit of the people we serve. We have a new Department of Education into which RSA and the Institute have been thrust. We are a part of the Office of Special Education and Rehabilitative Services, which is much like an island in an ocean because the great tide of the Department of Education is education related. We, however, are much more than that, and together we need to "educate the educator," to bring to the people in the Education Department the knowledge of adult handicapping conditions and disabilities in rehabilitation as well as the needs of children and the needs of older people. And in so doing we can insure that there is a constant relationship between the Education Department and the Department of Health and Human Services. We have a Secretary in Health and Human Services and a Deputy Undersecretary who are very sensitive to disability issues, and the opportunities for that interchange are very great indeed. We can make a great deal out of this new situation, but it will take a lot of coordination and hard work from everybody concerned who has an interest in disability and disabled individuals and their service delivery and research needs. But we can do it, and I am ready, willing and able. I know you are too.




*Subsequent to the addresses presented by Drs. Giannini and Martin, the following issues were raised from the floor and responded to by the Director and the Assistant Secretary.*

**Dr. Paul Hollman**
**University of Wisconsin-Stout:**

**Q.** Dr. Martin, we have heard you speak quite a bit this morning on early childhood education which is very important and probably has been neglected. But there are those representing the vocational aspects too, and I wonder, would you address that please?

**Dr. Martin:**

**A.** Actually, I used the early childhood example to illustrate the basic proposition that the new research institute has a new challenge and authority and the fact that we have already begun talking about how we can work together without duplication of effort. But I would add that the adult community, both disabled individuals themselves and rehabilitation specialists, have expressed to me some concern that, because of my past interest in programs for elementary and secondary education, they might encounter a "getting lost in the shuffle" phenomenon. I think perhaps only the experiences we have together over the next few months and years will truly reassure people, but I would point out that our concerns have already come together—even in the program which is most closely identified in people's minds with children—Public Law 94-142. The fact is that this law has a much broader concern than children, and that has been true throughout our history. Our first and longest standing program we have administered is the Captioned Films for the Deaf Program, a program which has had as its focus for a number of years the adult deaf community. We have also worked with the Rehabilitation Services Administration in the support of such matters as post-secondary and technical education projects for the deaf. Similarly, I had asked the President, and it is now reflected in the budget, for a million and a half dollars to begin adult education programs for disabled adults, as well, as part of the outgrowth of the funding package that we began some years ago. Those programs which began for the deaf have been expanded in a number of communities to encourage the participation of disabled adults in college and university programs, but not much has been done to stimulate the participation of disabled people in adult education programs, and so we will be funding some models there.

The exciting part of the new job is, in fact, that one does not have to limit oneself to people aged 21 and under.

**Dr. Fredric Kottke**
**University of Minnesota:**

**Q.** I am very pleased this morning to hear both you and Dr. Giannini talk about the development of a comprehensive program of rehabilitation which has really been the thrust of the R&T Centers since their institution and even before that. You mentioned the concept of these as "the building blocks" of the new institute. I think of it the same way because it really is the only continuing group of people committed to continue research in this area of rehabilitation for handicapped persons. I have concern, however, that the plan for financing is divisive rather than coordinated in that, in spite of the fact that over the past eight years we have asked for the kind of a program that allows us to work together and cooperate so that we are not competing in a divisive way, the limited funding plan again this year says, "You will compete among yourselves for the scraps of money that are available." And I hope that both Dr. Giannini and you, Dr. Martin, think about this, because if you are going to have inter-institutional cooperation it cannot be built on inter-institutional competition for projects. As a matter of fact, the whole R&T Center concept is a program concept—a critical mass of people getting together to work on problems that are long-term research with progressive development as we get new information so that we can eventually resolve in a meaningful way the problems that the whole gamut of handicapped people experience.

The idea of regional centers grew out of the realization that one could not build a single center in the United States without depriving all the rest of the country of the resources of people that were available, and by placing regional units in universities we can make use of the resources of the universities, make use of the cooperative arrangements that existed there, and have a very significant multiplier effect for research, for stimulation of new ideas, and for teaching, which is by far the best way of dissemination and application of new information. If we are going to be successful, however, it is not as a group of universities each one working alone on their own problems, but through cooperation between centers and between universities. We have been trying very hard to build this kind of inter-institutional cooperation with a cement that makes it possible for really free exchange of information without the sense of competitiveness, without the fear of piracy, without the secret enclaves that so often occur in defense of one's own activities when we have a competitive program. And yet again this year, possibly with inadequate feedback to Dr. Giannini because she certainly did try to communicate, I feel what is proposed as a competitive plan deserves reconsideration of a better way of producing a collaborative plan. So I would like to point out that we are very enthusiastic about what you are doing and the beginning of the development of the Institute, but within our own little needs and programs we see this as a problem to be resolved.

**Dr. Giannini:**

**A.** I do appreciate what Dr. Kottke has stated. I assure you that no divisiveness is intended. First of all, let me clear the record. This plan is not intended to change collaborative efforts that have been in place for years, but rather to strengthen them. This is not a divisive method based purely on competition, but rather to have academic excellence surface. I also would like to remind you that monies that are "competitive" are just in-house for R&T Centers alone. Hopefully this will allow you to be creative and innovative within your programs without too much disturbance. You could also augment your ongoing programs and still allow the Institute to meet some of the mandates that we have during this year. Fiscal year 1980 is diffi-

cult because we are at the same level of funding that we were last year, and yet we have a lot of new responsibilities. Therefore, I did a lot of thinking and soul searching on how we can both manage to meet our goals and objectives. In 1981, of course, we will be in a different era. We will have, hopefully, more money, both for R&T Centers and our other projects. With what we have initiated this year as a base we can not only expand your basic R&T Centers but also expand your R&D projects.

The other difficult area that we have to face is that we at the Federal level cannot respond to your inflationary needs. I had hoped that many of you would have year end money, and I know that a number of you do. I do not see any point in taking money away from those of you with balances and giving it to others when you still have problems in-house. That was the reason that I did talk to a number of you. I thought that there may be some local issues that I did not see properly and that with your explanations I could view and assess a little differently. To sum up, let me just say—on the one hand we have the same amount of money that we had last year. On the other hand we have a tremendous area that we have to cover. I think that for one year if we could pull ourselves together to do this, it will be the most effective way to go.

I would be glad to discuss this further with you, collectively or individually. I am willing to search for a better solution short of giving lumps of money indiscriminately to certain R&T Centers. I do not think that is justified, and I do not think it is fair. The R&T allocation of $1.2 million will give all of you an equal opportunity to augment your programs.

**Dr. John Goldschmidt**
**Northwestern University:**

**Q.** Dr. Martin, I have a comment and a question to address to you particularly, and perhaps Dr. Giannini might join in. For some time the colleagues that you see here and around the country have concerned themselves about the possible consequences of entering the realm of education as a health-related service system. You have assured us this morning that we will not get lost in the shuffle in such a large, complicated, intertwining network. I am more concerned, however, about the shuffle that the children might get into and would like to address a particular question to you.

The child who is mainstreamed, who is sent into the community, who gets into the hands of special education teachers, who goes through prescribed local programs, protocols of educational activities—will they have adequate diagnoses beforehand? What linkages will there be for an appropriate, adequate, discrete diagnosis of the problem that the individual child has prior to their being mainstreamed and put into common protocol? I do not expect answers from both of you on this. I think it is a researchable problem, and it requires a great deal of thought so that the individual child does not get lost between the health service field on the one hand, who may know little about learning disabilities, through vocational, through senescent stages of life cycle; and on the other hand the educational cycle which may think that they have the diagnoses well at hand when oftentimes that is not the case.

**Dr. Martin:**

**A.** Let me try not to be premature in answering what is a sophisticated question. Part of our interest in the past few years has been to stimulate training within the pediatric group concerning P.L. 94-142, and I have met with various people in that field and taken part in conferences. We have also spent some time with the Academy of Child Psychiatry in a similar series of discussions. In those meetings there has been raised a number of times a concern among physicians that the original identification of children with different disabilities is not specified by the Federal statute with regard to who should be involved in that process. Part of this is the historic separation of education from the Federal government. All of the states have state statutes which cover the subject of how a child is identified. They vary, however, from state to state. In general, when the Congress passes education legislation it does not get over into setting standards within state activities. And the legislation did not specify which specialists had to be employed by the states in the identification process, although the Act does spell out that, in fact, the children need a multi-disciplinary look and that appropriately trained specialists must be involved.

Now, the logical and simple solution to concerns of this kind might seem to be for the Federal law to mandate the requirements for various specialities. In practice, however, there would be problems, especially because of the traditional separation between the states and the Federal government in this area. It is an issue that I know has been raised to the Congress in oversight hearings, and I expect it will continue to be raised. For example, questions about the Act are impelling us to get into the issue of related services. We already are facing how to make policy judgments as to which specific related services must be provided for handicapped children in order to carry out the intent of the law, and I think that both the Department and the Congress will be facing issues of this kind. In the meantime the best advice I can give to organized groups—educators, rehabilitation specialists, physicians, and others—is that this is a problem that has to be confronted at the state legislative level in those states where the state does not now provide for specialists with appropriate training. I think it will be difficult to get the Congress to mandate universal Federal standards in the education area, although obviously they have in health related areas. But I do not see the problem as being any different for mainstreamed children than for children in special schools or special classes. The basic issue is "who decides when a youngster is handicapped, who are the members of the team, what are their credentials, and ultimately who has the general supervision of the treatment process?" All are tough questions.

**Dr. Giannini**

**A.** There is in place now a training program, with the cooperative effort of BEH and the Academy of Pediatrics, that will have specific training programs on local and national levels by an assigned faculty from the Academy of Pediatrics. I also think that within the law, if I remember correctly, the clinical support services are quite clear. However, the problem is that the funding does not follow the mandate on the local level, so as you well know, the local communities and the local school boards have to decide how they are going to finance it. Until that problem is resolved it is going to continue to be a vicious circle.

# RTC Input Into the NIHR Long Range Plan

**Moderator - Joseph Fenton, Ed.D.**
**Special Assistant to the Director**
**National Institute of Handicapped Research**

**John W. Goldschmidt, M.D.**
**Associate Project Director**
**Northwestern University**
**Medical R&T Center**

*The legislation (P.L. 95-602) establishing the NIHR sets forth specific research areas, of which the RT Center Program constitutes a major portion. It was, therefore, important in the development of the NIHR Long-Range Plan to include identifiable programs that RT Centers, as well as other NIHR programs, might project over the next five years.*

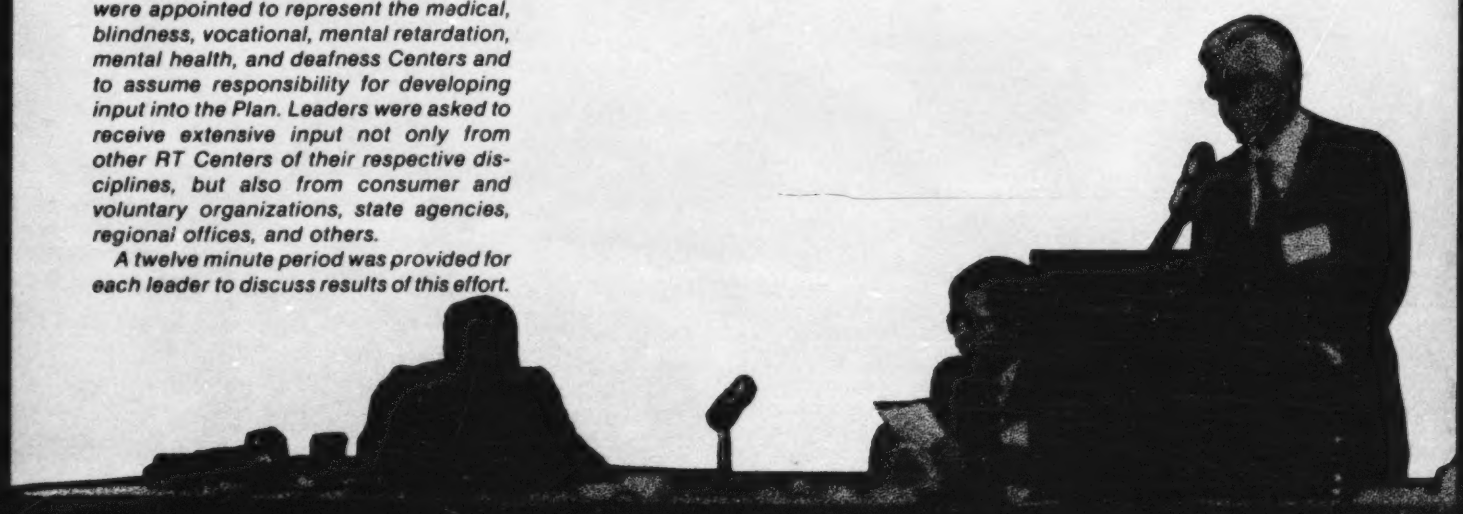
*In accomplishing this, an organizational structure was developed which was felt could best involve faculty of all types of RT Centers. Accordingly, six individuals were appointed to represent the medical, blindness, vocational, mental retardation, mental health, and deafness Centers and to assume responsibility for developing input into the Plan. Leaders were asked to receive extensive input not only from other RT Centers of their respective disciplines, but also from consumer and voluntary organizations, state agencies, regional offices, and others.*

*A twelve minute period was provided for each leader to discuss results of this effort.*

## Medical Research Plan

Dr. Brammell and I were requested to accept the task of participating as coordinators in long-range planning for NIHR at a meeting in Washington, DC by Dr. Giannini, Dr. Fenton and other NIHR staff members and consultants. A meeting of representatives of the Medical R&T Centers was held at the Rehabilitation Institute of Chicago. Some 24 members of the medical rehabilitation disciplines including members of ACRM and AAPHR participated by invitation. One hundred twenty-six projects were generated which addressed identifiable and researchable issues posing problems of high priority for resolution by medical R&T Centers. Specific research problems and the relevance for the need to address each issue were recorded. For each problem area, strategies, activities, demonstration, and investigative methodologies were recommended. It was not an editorially consistent and cohesively written document by the conclusion of the first meeting, but it was a representative initial draft. Byron Hamilton, Paul Corcoran, Fred Fay, Gerben DeJong, Bruce Maloof of ABT, Inc., and many others gave up valuable weekends in order to consolidate the ideas and further refine the plan in the short time available.

There are currently 46 pages to the medical recommendations and there are



certain themes which run throughout. We recognized first of all that rehabilitation is a process through which the patient or client progresses toward optimal performance. It is not something that is done to the client, for the client, or on the client. The patient or client is **assisted** in the process of achieving the goals set. Ideally, if able, the individual sets the goals assisted by family and professionals. It was recognized that there needs to be a continuity in the process, and the theme of continuity was preeminent in our minds as we approached the final taxonomy or outline for presentation of the plan.

The outline tracked the continuum of care through six component elements and addressed illustrative issues in each of the following topical areas: (1) Prevention, (2) Diagnosis and Functional Assessment, (3) Natural History of the Disability, (4) Rehabilitation Medicine Management, (5) Environmental Adaptation and Independent Living, and (6) Community Follow-up Services and Health Maintenance.

In addition, certain contemporary themes of rehabilitation were important to consider:

- Rehabilitation of the vocationally needy had to be expanded now to include the young and the elderly. It had to include other underserved persons, populations, and socio-cultural conditions that differ in varied regions.
- The management of man-machine dependency that has evolved and created advancements in life-support systems while often creating more and greater problems of physical impairment.
- The problems and themes of quality of life and independent living had to be addressed with some forcefulness throughout this continuum of concern for life-maintenance and rehabilitation.
- The responsibility to contribute to improvements in the planning, management, and evaluation of rehabilitation service delivery systems is a continuing challenge.
- The current capacity and the further development of the capacity to undertake research in medical rehabilitation remains a problem. Inadequacy of research manpower, mind-power and funding continue.

I will list by general issue some of the illustrative problems in this continuum of care as presented in the medical plan and present samples of possible research approaches within each. The methodology and research design cannot be detailed, but the goal to be attained and the general strategies are set forth as examples.

**Prevention**

- Expand training of health professionals in genetic counseling and evaluate the effect of genetic counseling on reducing developmental disabilities and MR.
- Demonstrate and evaluate educational programs for teenagers, leading to greater changes with respect to birth-related disabilities, auto accidents, sporting injuries, firearms use, drug and alcohol use, nutrition, smoking, physical fitness, and other factors related to high risk populations.
- Demonstrate the value of various approaches to improving pre- and neo-natal services and public pre-natal care education programs in preventing birth defects.
- Demonstrate the value of joint efforts among employers, insurers, and media with regard to prevention of industrial and household accidents.
- Undertake research on the cost-effectiveness of early detection and screening for hypertension. Perform research and development on methods of improved compliance with prescribed medical regimens for management of hypertension.
- Investigate factors in obesity, weight control, proper nutrition and how they affect arthritis and other chronic degenerative illnesses.
- Devise research models which can elucidate the role of disability payments in the epidemiology of chronic back pain.
- Identify long-term disabilities related to marijuana, cocaine, and other recreational drugs.
- Improve the understanding and treatment of contractures and other limitations of joint motion secondary to inactivity.
- Undertake research into the causes and prevention of pressure ulcers in bed-confined persons and wheelchair users.
- Pursue research and development to improve neurogenic bladder management.
- Develop better methods of early prevention, recognition and management of thromboembolic complications, osteoporosis and heterotopic calcification, postural hypotension, autonomic dysreflexia and thermo-regulatory disorders.
- Undertake research into the prevention of pulmonary infarction, atalectasis and pneumonia in bed-confined patients.
- Investigate health maintenance inter-

ventions for disabled persons such as nutritional and recreational programs.
- Research and demonstrate the value of wheelchair sports in physical fitness programs for handicapped.
- Research the effects of sensory deprivation, body image alteration, and cosmetic appearance on the adaptation of the person to disability.
- Investigate psychic, spiritual, and religious factors in adaptation to disability.
- Develop strategies to reduce the psychological regression that accompanies prolonged immobilization, bed rest and lack of participation within the mainstream.
- Research the causes and prevention of suicide and other self-destructive behaviors among disabled people.
- Improve physician education with respect to the prevention of recurrence of illnesses or injuries which cause disability.
- Improve physician education with respect to prevention and to the alleviation and provision of basic primary and medical and dental care for disabled people.
- Develop and evaluate models for early recognition of disabilities in underserved populations, including Native Americans, Blacks, Hispanics, migrants, and other rural populations.

**Assessment**
- Develop human performance laboratories, having the capacity to quantify mobility and neuromuscular disorders and their effects.
- Develop simple, reproducible, inexpensive techniques for measuring spasticity.
- Develop inexpensive, non-invasive cardio-respiratory monitoring and telemetering systems for use with a physically disabled individual with associated cardiopulmonary impairments.
- Apply the vast existing body of knowledge about electrodiagnostic procedures.
- Management of chronic pain syndromes.
- Long-term performance outcomes in growing children with disabilities.
- Develop predictors of long-term vocational outcomes to provide a realistic basis for educational and vocational planning.
- Investigate the influence of behavioral variables on functional outcomes and various disabilities.
- Develop normative data on the relative value of various living arrangements, productivity levels, and lifestyles of people whether ablebodied or disabled.

**Natural History**
- Acquire disability data on computerized basis, statistics annually updated through existing census data, public health registries, agencies of the government and private facilities having direct contact with patients and clients. This would help us in the identification and early screening for at-risk populations for disability.
- Establish a national service center, similar to the Center for Disease Control in Atlanta, for the purpose of data acquisition, storage, retrieval, and dissemination with respect to the natural history of disability.
- Acquire statistics on disabilities by etiology, anatomic and physiologic impairments, performance deficits, and behavioral dysfunctions, mobility, sensation, coordination, communication, interpersonal relationships, ADL and other subsets of impairment and functional loss.

**Rehabilitation Medicine Management**
- Expand demonstrations of improved emergency care, evacuation, and referral to special centers after burns, multiple trauma, brain and spinal cord injuries in particular.
- Develop diagnostic measures of the extent of tissue damage and development of methods for eliminating the extent of tissue damage and enhancing neurologic recovery in the period immediately following a brain or spinal cord injury.
- Develop centers for neuro-biological studies of spinal cord regeneration.
- Critically evaluate the role and relative merits of the numerous proprioceptive and sensory facilitation techniques which are used empirically in the management and therapy of neurologic disorders in order to distinguish a specific therapeutic effect from the general benefits of attention and stimulation which accrue from therapeutic interventions.

**Environmental Adaptations and Independent Living**
- Develop the rehabilitation engineer as a routine functioning member of the rehabilitation team, not just for research but to take an active part in developing and delivering services such as general equipment evaluation, designing construction of special devices, modification of commercial devices and assistance in device selection and prescription, and rapid commercialization and marketing of rehabilitation technology through specific research and development activities.
- Develop a direct smoothly functioning link between NASA and NIHR to assure rapid application of technical developments from the space program and to acquaint NASA personnel with the engineering needs of disabled individuals.
- Carefully study financial disincentives to gainful employment.

**Health Maintenance and Follow-Up Services**
- Every medical, dental, and nursing student should be trained in the basic attitudes, skills, and knowledge content areas having to do with disabilities as they relate to their respective health disciplines.
- Post-graduate residency training programs in the medical and surgical specialties should include training in the rehabilitation aspects of disabilities.
- Mental health professionals need the addition of curricula concerning psychological aspects of disabilities in their basic training so that they conceptualize more than just specific problems of mental health and mental disease.

There are many more issues, recommendations, and discussions contained within the complete document. Hopefully, you will all see the document at a future time. We have placed great emphasis on program versus project development of these research areas, and we recognize the strong need for research capacity building and further development, without which we cannot pursue any of these as projects in any meaningful way.

*Following Dr. Goldschmidt's presentation on the Medical RTC Research Plan, additional comments were provided by the co-chairman of this group, Dr. H.L. Brammell, Director of the Medical R&T Center at the University of Colorado. Dr. Brammell suggested the value of an identifiable section of the NIHR Long Range Plan which would deal specifically with the research activities of the RT Centers. It was further pointed out that many of the researchable issues in the medical plan cut across many specialty areas and therefore highlight the need for collaboration within meaningful research efforts.*

## Blindness Research Plan

**Thomas S. Baldwin, Ph.D.**
**Project Director**
**University of North Carolina at Chapel Hill**
**Blindness R&T Center**

Let me introduce the approach that RT-24 took to the blindness section of the Plan. First, our group had some problems that were perhaps a little bit different from most of the other groups, which may have been good or bad. For one thing, we are the only R&T Center on blindness, whereas a number of other areas concerning handicapping conditions have several centers and have been in operation for some period of time. RT-24 had been in existence for six months at the time we were asked to participate. Some of my colleagues who represent other groups suggested that in their particular professions there were other long-range plans which they had been able to integrate. Unfortunately, most of the work in the area of blindness has been somewhat project oriented and had never been pulled together in any cohesive way. While we faced some problems, we were able to draw up a plan representing a course of action without a lot of previously held biases from the field of work for the blind.

There were two major approaches that we used in developing our plan. First, we surveyed some 208 public and private agencies involved in work for the blind, including all 100 state vocational rehabilitation agencies and state special education departments, and 108 of the major private and public organizations involved in work for the blind. We received 55 responses, identifying over 100 separate problem areas, in less than three weeks.

In addition to our national survey of some 208 agencies, we had very strong support from our National Advisory Council which represents consumer, public, and private organizations involved in work with the blind. The Council met with us on a number of occasions throughout January, February, and March to assist in the development of the final plan.

The problem at the beginning was the degree of specificity in the development of our plan. We realized early that the identification of broad problem areas, under each of which a large number of specific projects might be undertaken, was probably the best approach. The first preliminary draft was produced on January 29, followed by a meeting with the Advisory Council on February 4 and 5. A second draft was developed by February 19, and the Council convened at the end of February to establish priorities and funding. There were 62 major problem areas that were identified in the final plan. Under any one of these a number of projects might be generated. Unquestionably, the largest problem that both the surveyed agencies and the Advisory Council identified was employment. Under the general area of EMPLOYMENT in the field of work with the blind a number of problem areas were noted:

- Unemployment as probably the single strongest problem
- Underemployment (i.e., use of sheltered workshops when a person could be productive in a competitive work setting)
- Incentives to employers to assist employed blind workers to progress through the company career ladders.
- Job retention of the adventitiously blinded individual (since many of these people, because of the trauma associated with the loss of vision during the working years, simply give up; whereas, with appropriate training many of them could retain their jobs)
- Pre-vocational training or the lack of pre-vocational training to permit blind persons to know what options are available to them rather than having the stereotypic notions that there are very few careers which they can enter, such as music or sheltered workshop work
- Orientation and mobility training, particularly for the multi-handicapped blind

The second biggest area as a whole that was identified was BEHAVIORAL AND SOCIAL ADJUSTMENT of blind people, with the following major problem areas:

- Behavioral and social adjustment particularly for the pre-school child, since failure to develop normally through this period prevents him or her from catching up in behavioral and social adjustment
- Interpersonal relationships of blind people throughout the life span
- The self-image problems that blind/visually impaired people typically encounter

Under the category of SYSTEMS BENEFITS, a surprisingly large number of major problems were identified, among which were:

- The question of the quality of services that are provided by both public and non-governmental agencies
- Delivery of services in the home and in neighborhoods to prepare clients for independent living (since many people who are blind simply refuse to leave home to come to a rehabilitation center for an extended period of time. This is being dealt with now through the independent living services program that is being implemented, but we really do not know how best to deliver these services to blind people in their homes or in their neighborhoods.)
- The lack of job identification and placement services that would permit a rehabilitation counselor to know how best to work with industry to find employment for the blind and visually impaired
- The failure to apply research done in the area of low vision, particularly until some specific Federal action is taken (i.e., the ophthalmologist and the optometrist know well how to deal with corrective lenses or devices to assist a person with low vision to make the best use of residual vision, but they cannot afford the time to work with and train the client; therefore, low vision devices frequently are not used.)

Prevention of blindness and the fact that blind people are not aware of available services were also considered to be major areas of concern. Even though North Carolina has a separate agency for the vocational rehabilitation of the blind, it is amazing how many people have called the Research and Training Center since it was established and have stated that they were not aware of the state agency and the existence of the services it offers.

I have touched just very briefly upon the number one priority category in our plan. The problems that were identified as number two and number three priority have not been mentioned. However, the resources likely to be available over the next few years will probably all be absorbed through top priority issues.

# Vocational Research Plan

**Vernon L. Glenn, Ed.D.**
**Project Director**
**University of Arkansas**
**Vocational R&T Center**

The vocational R&T Centers, University of Arkansas, West Virginia University, and University of Wisconsin-Stout, are designated as vocational centers established to conduct programmatic research and training in the psychosocial/vocational areas of rehabilitation.

The three R&T Centers are alike in many respects in that each responds to specific information needs in the areas of rehabilitation management, program evaluation, client intervention strategies, and service delivery systems. Each has an ongoing involvement with a vocational rehabilitation state agency; each disseminates research and training information on a national basis; each is organized to achieve its mission through research, development, training and evaluation; and each of the three centers serves as a sponsor and coordinator of one of the three national studies on rehabilitation topics through the Institute on Rehabilitation Issues. This background information is provided as our past and present activities strongly influence the projected needs in the psychosocial/vocational area for the next five years.

Because of the short time-line established by the National Institute of Handicapped Research for submitting our plan, we did not have sufficient time to adequately develop a long-range plan that clearly outlines the needs in the psychosocial/vocational areas of research and training.

The format used in the plan identifies research under three areas.

**1. Research Contributing to Individual Client Benefits:**

**Employment**

The major thrusts of research in this area are to identify barriers to employment of handicapped persons from both the perspective of the handicapped person and from the perspective of the professionals who are delivering services related to employment, vocational evaluation, vocational training, and placement of handicapped persons; secondly, to improve the validity and reliability of the vocational evaluation methods presently used to place and train the severely handicapped persons; third, to conduct longitudinal research on vocational development, vocational adjustment, and vocational functioning of rehabilitation clients; finally, to conduct research on methods of producing more active involvement of clients in vocational planning, evaluation and placement. The complete report includes a description of 35 projects that are targeted at these objectives.

**Vocational Training/Education**

There is a strong need to identify services that are presently provided by professional staff that could be taught to parents of disabled children. Programs such as language instruction that are presently provided through formal services could be instituted in homes if parents were trained. There is also a strong need for research on methods of better specifying competencies and performance objectives and alternative learning assessment techniques with diverse disability groups. Training in specific competencies could then be improved so that vocational evaluation, work adjustment and vocational training programs would be enriched.

**Housing, Mobility, and Transportation**

Research is needed in these areas to identify the effect on housing needs and transportation needs of the handicapped population as a result of deinstitutionalization. It is hoped that these types of surveys would also allow cost effective programs to be established by communities to solve the independent living needs of handicapped persons within the restrictions naturally placed on the community by their housing and transportation characteristics.

**Communication**

Many programs being proposed by different states in the development of the independent living services include components of hiring and training handicapped persons to provide independent living services. Most of these people have not been trained in communication skills, interpersonal skills or supportive counseling. Research is needed to develop methods of training these handicapped groups to deliver services presently being provided by non-handicapped professionals. In addition, there is a need to examine some of the new technologies in computer applications and biofeedback methodologies to improve communications among handicapped persons and between professionals who deliver services and handicapped persons who need information, training, and other services.

**Behavioral/Social Adjustment**

Research in this area is one of the major thrusts of Vocational Rehabilitation Research and Training Centers. Over 30 specific

projects are included in our complete report of a research strategy. These projects range from the need to develop techniques to shift the responsibility for behavior change and growth from the professional helper to the handicapped client, the need to develop vocational decision-making skills and abilities in rehabilitation clients, the need to identify the interpersonal variables that influence the adjustment of handicapped persons, and the need to analyze the environment in terms of factors that are related to successful and non-successful coping with disability, and the need to identify and develop methods of producing generalization of successful coping skills across different settings for different disabilities. The scope of the research in this area includes the identification of successful intervention procedures in fields allied to rehabilitation as well as to develop new methods that will enhance psychosocial adjustment of handicapped persons.

**Recreation**

The thrust of this research is to develop methods that will facilitate adapted physical education and recreation therapy for the severely handicapped adult as well as to identify recreational barriers encountered by the handicapped during vacations and methods of decreasing these barriers in a cost effective program.

**Environmental Accessibility**

The objectives of research in this area are to identify and utilize situational-environmental resources that will aid handicapped persons in overcoming barriers in psychosocial adjustment at all ages. These projects range from studies on the effective utilization of electronic aids to the application of other adaptive equipment and ergonomic designs to facilitate the delivery of rehabilitation services and to enhance independent living of handicapped persons.

**Assessment**

There are many high priority needs for research on methods of identifying discrepancies between vocational evaluation information and client performance in vocational training programs as well as in work settings. In addition, research is needed on assessment of human service delivery systems, problems, and particular strategies that promote successful adjustment both within the facilities and in independent living. Evaluation of employment potentials of severely handicapped persons and evaluation of therapeutic and cognitive gains as a function of client—service delivery provider relationships are needed. It is hoped that the assessment strategies represented by the 15 research projects described in the long-range plan would improve our knowledge of handicapped persons' needs and rehabilitation service delivery needs.

**2. Research Contributing to Improvements in the Planning, Management and Evaluation of Services for Disabled Persons**

Effective and efficient service delivery systems is an area where Vocational R&T Centers make a major contribution to rehabilitation agencies, and there is a continuing research and training need in this area because of the following:

(a) In 1970 the population of the disabled in the United States was estimated at 11 million. Beginning in 1980, ten years later, this population is estimated to exceed 35 million, with more than 10 million being categorized as severely disabled. It is projected this increase will continue due to the increase in population, the increased life span and the continuation of disabling conditions caused by disease and accident.

(b) Recent legislation passed by the 95th Congress has expanded services to the disabled in all areas of living. This includes equal opportunities in housing, employment, education, removal of architectural barriers, the involvement of consumers in policy decisions and expanded services to include independent living rehabilitation.

(c) Accountability in human service agencies will receive greater emphasis during the 1980's. The public as well as organized consumer groups are demanding high quality services while economic conditions are requiring more resourcefulness in the delivery of rehabilitation services.

Research and training in the total management area is greatly needed to identify ways to effectively use personnel and resources to provide high quality services to the disabled population.

**3. Research Contributing to the Advancement of the Capacity to Conduct Research and to Store and Disseminate Information**

Research outcomes, in order to have impact on the field of rehabilitation, must be reflected in usable procedures and techniques. However, the skills and processes of research are much different from those required in the service delivery process. Because of these differences in languages, methodologies, processes, and goals researchers and practitioners view hypotheses and problems from different perspectives and within different frameworks. This makes effective utilization of research outcomes extremely difficult.

There is need for research in the area of storing information which can easily be accessed by researchers, and there needs to be a national effort in the areas of vocational evaluation, work adjustment, and facility management to design research studies so that research outcomes can be easily translated into practical procedures and techniques.

Information about rehabilitation services abounds in professional journals and literature. But there is a need for research and training both to develop a system and to train practitioners in the effective utilization of research for solving practical problems.

Projects were developed under these three categories using the following format: (1) Title of Project, (2) Statement of the Problem, (3) Planned Research Strategy, (4) Potential Implications of Research, and (5) Projected Costs.

In developing the projects we solicited ideas from our Consumer Advisory Committee members, other university personnel, facility personnel, and representatives of the Council of State Administrators of Vocational Rehabilitation.

The final plan submitted to the National Institute of Handicapped Research represented 199 projects that have potential for contributing to the solution of problems and needs of handicapped populations in the psychosocial/vocational areas. The projects are respondent to the multifaceted rehabilitation process in human service agencies which requires research and training over a broad and diverse area of human functioning, which includes mobility, communications, cognitive intellectual development, personal and/or social functioning, vocational functioning, developing intervention strategies in training, counseling and environment changes, and impacting the policy programs and management systems in human service agencies. Much work still needs to be done to refine the projects and identify their potential contributions and impact on improving the quality of life for the severely handicapped population.

# Mental Retardation Research Plan

**Rick F. Heber, Ph.D.**
**Project Director**
**University of Wisconsin**
**Mental Retardation R&T Center**

The plan for mental retardation really applies to all developmental disabilities in the main. We addressed the whole issue of developmental disability, except for those aspects that we felt would be covered by the medical rehabilitation group. All three R&T Centers in mental retardation—Texas Tech University, University of Oregon, and University of Wisconsin were heavily involved in this plan. Special credit is given to Phil Browning who very kindly spent a couple of weekends in Madison to assist in compiling the materials. We also had vigorous input from the American Association of University Affiliated Programs (AAUAP) through the participation of Seldon Todd, Executive Director of the University Affiliated Facility in Portland. Gail O'Connor represented both the American Association on Mental Deficiency and the Scientific Advisory Board of the National Association for Retarded Children.

Our group tried to address itself to the broadened scope of the new NIHR mission, as Dr. Giannini had asked us to look at the problem from the total needs point of view because of her responsibility for interagency coordination of effort. Our group was particularly concerned with some areas that impact on prevention that seem to have fallen outside the purview of the National Institute of Health over the past decade.

Work was initiated by trying to assess the progress that had been made in this field over the past 20 years during which a major effort at the national level has been mounted. Up until 1960 the view of mental retardation was "out of sight, out of mind." The 60's marked the initiation of the first major effort to recognize and confront mental retardation as a national problem and brought accomplishments during that decade. The national network of diagnostic and evaluation centers, the University Affiliated Facilities, the mental retardation R&T Centers, and major staff training efforts for both research and professional personnel were mounted in institutions throughout the country. Near the end of the decade the American public was really shocked to learn of the inhuman conditions that were facing literally hundreds of thousands of mentally retarded people who were warehoused in our large state institutions. These as well as other startling facts set in motion the dominant trend in this field in the 70's—the deinstitutionalization of these people and their return to the community. The 1970's also marked the first real recognition of the full citizenship and legal rights of mentally retarded people with passage of three major pieces of Federal legislation, PL 94-142, 93-112, and 94-13.

So we have made major advances during the past 20 years; we can prevent mental retardation in a few cases; we can cure it in a few cases; and retarded behavior can now be recognized and significantly altered or modified through rehabilitation. But despite these gains it is clear that the two most sought after goals in the 1980s are (1) to prevent mental retardation from occurring, and (2) where we cannot do that, to enable persons with mental retardation to live the most satisfactory and socially productive lives possible.

We need, most of all, to emphasize prevention. Despite the substantial research efforts which have been supported principally by the NIH over the past 20 years, specific positive mechanisms are still understood in less than 10 percent of the cases and in only a tiny fraction of these is there a present primary prevention capability. However, as our knowledge has advanced several promising areas of research and demonstration have emerged in which we propose that the National Institute of Handicapped Research must contribute and play a leadership role.

### Cultural-Familial Mental Retardation

It is estimated that up to 80 percent of the total population of the mentally retarded reflect no demonstrable pathology. This form of retardation, while substantially handicapping, is usually a mild to a moderate degree. Specific determinants remain unknown, but it is known to have a disproportionately high prevalence among economically disadvantaged groups in both cities and rural areas. It has a striking tendency to run in families and to perpetuate itself from generation to generation in the same family. Clearly, because of the numbers involved, no major impact in terms of prevention can be made without addressing the problem of the cultural-familial mentally retarded. We therefore have proposed that the following research areas demand special attention in the coming decade: (a) Investigation of the epidemiology of cultural-familial retardation, (b) Ideological research, (c) Research and demonstrations on prevention and amelioration, and (d) Research and demonstrations on effective and cost-

effective methods of rehabilitation through services which impact directly on the family as opposed to the individual person.

**Evaluation and Development of Follow-up Programs for Early Screening of the High-Risk Infants**

Many states have screening programs now to detect phenylketonuria and congenital hypothyroidism, but few have developed comprehensive, long-term follow-ups.

**Clinical Trials of New Medical Technology**

More than a decade after the development of electronic fetal monitoring and neo-natal intensive care, there are no definitive studies of their efficacy in preventing mental retardation, cerebral palsy, or other developmental conditions. These new technologies must be subject to vigorous clinical trial. Research must also focus on the development of interdisciplinary health care models for adult handicapped. While the University Affiliated Programs provide comprehensive health care for developmentally disabled children, no such models have been developed for adults. In addition to the epidemiology of cultural-familial retardation, we need more epidemiologic studies of severely handicapping biomedical conditions.

Aside from prevention, the other areas of research are in rehabilitation or habilitation—the behavioral training of the mentally retarded. Here our emphasis breaks down into research needs in the areas of (a) individual intervention with the mentally retarded, and (b) research efforts that need to be directed toward community integration.

**Age Range and Level of Severity**

We recognize that though the behavior of the mentally retarded can be improved significantly, it is a developmentally disabling condition which is likely to continue indefinitely and require a combination and a sequence of interdisciplinary or generic care, treatment or services which are of a lifelong or extended duration.

**Severity of Mental Retardation**

Over the past 10 years the predominance of emphasis, both in the development of services and in research support, has been on severe and profound mental retardation. This disproportionate effort has come to the point where it has concerned leaders in the field. Recently the president-elect of the American Association on Mental Deficiency saw fit to state, "By all means, let us maintain interest and investment in severely and profoundly retarded individuals, but at the same time let us rediscover mild and moderate retardation and invest in those levels of renewed research interest and necessary public support to sustain good research of high quality." Therefore, all of our recommendations apply with equal emphasis to all levels of severity.

**Vocational Preparation or Vocational Rehabilitation**

We need to develop new and refined vocational assessment, training, and placement technologies and expand demonstrations of these findings. We are very concerned with the question of social competence and mental health among the mentally retarded, particularly with the new emphasis on integration of retarded persons into the local community and away from the institutions. There has been little effort thus far made in the area of training retarded persons for social competency. It is well known that the mentally retarded are subject to a higher rate of mental, emotional, and behavioral disorders (the more obvious forms of mental illness), but in addition to that emotionality, motivation, etc. serve as impediments to effective community integration.

**Self-advocacy and Consumer Involvement**

We need to increase our understanding of the role and function of mentally retarded persons themselves as participants in self-advocacy and consumer involvement.

**Community Integration**

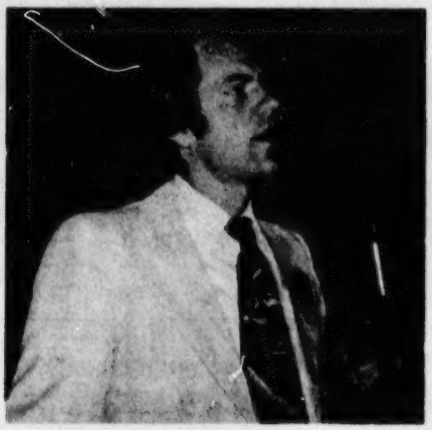
Efforts that are directed external to the retarded person are a major area of increased attention. Litigation and legislation have required the least restrictive objective to treatment of the mentally retarded. However, research demonstrations thus far in the movement out of the institutions suggest that the continuum from the more restrictive environment to the less restrictive environment is open to question. In order to enable retarded persons to maintain as independent a lifestyle as possible, we must give research priority to defining and empirically validating a sequence of movement from more to less restrictive alternatives. We need to develop program models of least restrictive environment, and then we need to show how such models can be translated into practice. The achievement of independent living and successful community integration is not possible by dealing with the retarded person alone, and a wide array of coordinated programs and support services which do not presently exist must be provided if we expect to reach the objective of least restrictive alternatives and community integration.

**Public Awareness, Acceptance and Accommodation**

Surveys have shown that the verbal attitudes toward mentally retarded persons have improved, yet there are other indications that public opinion is not necessarily associated with positive behavioral interactions toward retarded persons. We need to increase our understanding of public attitudes.

Our group was quite resistive to coming up with a dictionary of titles of specific studies. Rather, we focused on emphasizing what we think are the most promising and critical research areas. We were also most resistive to coming up with a cost or fiscal allocation for the areas which we proposed, but are agreed, with tongue in cheek, that MR/DD should not be allocated more than ten percent of the annual Federal budget for its plans.

# Mental Health Research Plan



**William A. Anthony, Ph.D.**
**Project Director**
**Boston University**
**R&T Center in Mental Health**

I want to make essentially two points similar in scope to what the other group reporters have discussed: (1) the main themes that emerged from our information gathering process, and (2) how we went about developing these main themes, that is, the actual process we used to gather input from the field.

I want to provide a little bit of history first, and I would like to focus this history on the whole area of rehabilitation of people with psychiatric disabilities. In other words, why do we need research and training efforts in the area of psychiatric rehabilitation? The answer is really very simple. The reason is because our failures in this whole area have been so well documented, are so obvious and so well publicized that we are now pushed to the point where we must start to deal with them. Perhaps a rundown of some of these failures will illustrate my point.

- The deinstitutionalization movement that promised so much and delivered so little.
- Recidivism rates are high and employment rates are low.
- Community-based facilities that have been set up are often rejected by the community and by the patients that are supposed to use them. Figures indicate that one-third to two-thirds of the patients referred to community facilities do not show up; 40-50 percent that show up do not come back after one session.
- Traditional treatment approaches that are used in in-patient settings simply do not produce rehabilitation outcome.
- Drug treatment, which was incorrectly hailed by many as the cure and certainly as a treatment which would preclude the need for rehabilitation, simply has not produced its promises.
- The VR system which also deals with the rehabilitation of persons with psychiatric disabilities is showing a decreasing percentage of people who are severely psychiatrically disabled being rehabilitated.

We have researched treatments that we now know do not work very well. Now it is time to research those things that in fact do produce some positive effects.

With the historical background in mind, let me comment on the process and outcome of our Center's contribution to the NIHR long-range plan.

**The Input Process**

The process we used to develop these themes was simplified in one way—there were no other Research and Training Centers in mental health, so there was no pulling or tugging between centers. We also did not need a big travel budget to bring everybody together. We did however, use our Center's advisory council composed of a broad-based spectrum of consumers, family members, professionals, state mental health directors, VR directors, and others for input. A great deal of Center staff time was spent developing and mailing a survey to interested consumer groups, state mental health and VR directors, practitioners in both rehab and mental health, legal advocates, etc. These forms were very open ended and we asked the recipients to exert a good bit of effort in order to give useful input. They had to tell us what some of the research and training gaps in the field are, why these research and training gaps are so critical, and if possible, to suggest potential projects which might be able to meet these gaps. We demanded a lot of our respondents, and they came through. Our Center now has over two hundred returns on the research forms and over two hundred returns on the training forms containing over 900 pieces of information as to what the research and training needs in this field are.

**The Major Research and Training Themes**

From all this data we outlined what we thought were the critical themes, i.e., the critical research and training issues that need to be addressed. Some of the major themes are:

**Training**

One thing that kept coming up over and over again was that we are not presently training people in the skills and knowledge of psychiatric rehabilitation. We are not training people in how to do a functional assessment. For the most part, we are still training them in how to do a psychiatric assessment. We are not training them in how to teach client skills and how to become good teachers and educators of clients; what we are typically doing is training them in the traditional therapeutic and treatment approaches which research has already shown as not relevant to rehabilitation outcome. We are not teaching them how to coordinate and integrate the services in the community based on the client's needs.

Another theme—related to training—is that we need to develop and implement curricula capable of teaching client skills, not just ADL skills, but the skills needed to live, learn, or work in the community of their choice, i.e., self-control skills, parenting skills, interpersonal skills, etc. We need to research curricula already available and determine what is good and what is not and develop the curricula that are still needed.

**Models**

We do not have replicable service models in this field. We have certain programs that seem to show that they can impact clients better than other programs or agencies or areas. But it is very difficult to get those people to describe in observable, replicable, objective terms what it is in fact they are doing that produces this effect. We need to get people to research models and then to disseminate them in a way in which they can be replicated in other systems.

**Relationship Between Physical and Mental Health**

Can a treatment regimen that focuses on physical exercise, nutrition, and diet produce effects as good or better than some of the traditional treatment approaches? What about the person who is doubly disabled with both a severe physical and mental disability? We need to research the type of treatment that person receives, how accessible it is, and whether it is in fact meeting that person's needs. We need to look at the area of drug treatment. Most psychiatrically disabled clients who enter the rehabilitation system have been or are currently on drugs, yet we know absolutely nothing about the relationship between rehabilitation and drug treatment. We know things that scare us. For example, 30 to 50 percent of the people who are on drug medication should not be, either because it does them no good or because placebos would do just as well. But we do not know who those 30 to 50 percent are, so consequently everybody gets the treatment. We do not know if a good psychosocial treatment program that is replicable and objective can allow us to reduce the number of people that are on medication. Can the psychosocial program serve as a support for the reduction of medication rather than vice versa? Can rehabilitation support the withdrawal of medication?

**Consumer Involvement**

We also need to investigate the whole role of the consumer and the family member. They are a tremendously untapped resource in the area of rehabilitation of the psychiatrically-disabled person. We need to investigate how they can be better used rather than abused by the treatment system.

**The Career Development Pattern of the Psychiatrically Disabled Person**

We have a career assessment, a career counseling, a career placement process that is routinely done without much input from the person with a psychiatric disability. There are exceptions, but we need to investigate how to get the person with a disability more involved in that whole career process. We need to figure out how to do rehabilitation "with them" rather than "to them," as so often happens to a person with a psychiatric disability.

These are some of the most critical research and training themes that emerged. There were many, many others as we are dealing with 900 pieces of written data plus all the verbal input received from representatives in the field.

In summary, let me say this about our particular field. There is a lot we do not know, so we need good research efforts. It is frightening to look at the field and to know how little of it is based on data. And although there is a lot we do know, we do not use it, and this fact speaks to the need for training in this area. The third part of the equation is that there is a lot that we do not know but we act as if we do, and that is even more frightening!

# Deafness Research Plan

**Hilde S. Schlesinger, M.D.**
**University of California/San Francisco**
**Deafness R&T Center**

*Although Dr. Schlesinger attended the fourth annual conference she was unable to present on the panel due to illness. The following is an outline of the Deafness Research Plan obtained subsequent to her absence.*

The long range plans for deafness research within NIHR can be subdivided into (a) Technological Aspects; (b) Cognitive-psychosocial Factors; and (c) Demographic Information and Service Delivery Systems. All three of these areas can be traced through the life span of the deaf individual.

**In Infancy and Early Childhood**

A. Technological Aspects

1. Prevention
   - Further research into etiological factors of early childhood deafness
   - Research into genetics of deafness and genetic counseling
2. Diagnosis
   - Refinement of neonatal testing (cribogram)
   - Dissemination of information for neonatal and early childhood diagnosis
   - Development of a deafness curriculum for medical schools and evaluation of its effectiveness
3. Hearing Aids
   - Refinement of technology
   - Study of cost effectiveness; consideration of review by Consumer's Union of hearing aids and other prostheses

B. Cognitive-psycho-social Factors

1. Parenting the deaf child
   - Development of the most effective support system for parents of newly diagnosed deaf children
   - Production of standardized information to be available to parents in written and audio-visual form regarding audiology, hearing aids, language and speech development
2. Research on effects of multihandicapping conditions
3. Antecedents of communicative competence
   - Research into visual and auditory language processing
   - Research into relationship of language, speech, lipreading

C. Demographic and Service Delivery Considerations

1. Inclusion of demographic data regarding congenital and prelingual deaf children into census figures
2. Design of service delivery system coordinating medical, audiological and educational systems
3. Collection of cost figures and data related to medical insurance

**During School Years**

A. Technological Aspects

1. Identification of acoustic and visual requirements for mainstreaming hearing impaired children
2. Expansion of knowledge about visual processing of interpreted material
3. Development of standardized tests and measurements of greater validity and reliability

B. Cognitive-psycho-social Factors

1. Inquiry into emotional support to parents. It has generally been discontinued past toddlerhood; clinical evidence indicates that ongoing support is crucial to ongoing parent-child interaction.
2. Studies of the cognitive and psychological impact of mainstreaming
3. Studies of language and speech acquisition: the effect of bimodal (speech and signs) and bilingual (English and American Sign Language) input on language skills, academic skills and speech development
4. Further exploration of the relationship of language development and reading skills

C. Demographic and Service Delivery Considerations

1. Planning for the coordination of educational and mental health services to the school age population
2. Demographic study of multihandicapped school age population

**During Work Years**

A. Technological Aspects

1. Research into acoustic and visual variables that enhance working environments
2. Studies of noise pollution variables that decrease the likelihood of hearing loss
3. Refinement of telecommunications and radio usage

B. Cognitive-psycho-social Factors

1. Attitudinal research: clarification of existing attitudinal difficulties resulting in deaf unemployment or underemployment

2. Independent living skills: coordination of research for successful intervention with "low functioning" deaf individuals

C. Demographic and Service Delivery Considerations

1. Updating of census with reference to deafness - including minority group membership

2. Coordination of mental health services and accessibility of all adjunct services: halfway houses, inpatient services, residential treatment facilities, etc.

**In Older Years**

A. Technological Aspects: Etiological studies of late onset deafness

B. Cognitive-psycho-social Factors: effects of late onset of deafness (or adventitious deafness at any age)

C. Demographic and Service Delivery Considerations

1. Development of mental health services

2. Updating of census data - including minority group membership

3. Review of retirement homes for the aged deaf

**Boyce Williams, Director**
**Deafness and Communicative Disorders Office**
**Rehabilitation Services Administration**

*In the absence of Dr. Schlesinger, Boyce Williams was invited by Dr. Joseph Fenton, session moderator, to come forth from the assembly and present impromtu remarks on behalf of the deaf community.*

## Consumer Comments in Relation to RTC Research Responsibilities

Something I've heard this morning, and in years past, concerning your specific research responsibilities in RT Centers is that they often do not relate to people who are profoundly deaf. Why don't you do something about that? We do have two Research and Training Centers in Deafness now, and we are very pleased about that. Nevertheless, an R&T Center in itself specializing in a given disability cannot do the whole job. It has to have the involvement of all of the activities in research and training.

You have heard about Section 504 of the Rehabilitation Act of 1973 . . . Well, I have threatened Joe Fenton and others that when I retire I am going to start some lawsuits if people receiving Federal grants do not learn to communicate with deaf people! And that includes R&T Centers. Deaf people suffer from mental retardation, alcoholism, dope addiction, mental health problems and physical disabilities of all kinds. Therefore, you have here a joint responsibility to all become involved in order to provide at least a minimum of services to deaf people.

Last Friday I heard something that disturbed me very much, and I think it should disturb you too. The Federal government, in its infinite wisdom, is moving to block out policies in independent living services. I am speaking in the interest of 1.8 million people who have total or almost total hearing loss. Many of those people have been deaf since birth or early childhood. Their adjustment problems are very difficult and challenging. Out of that 1.8 million my best guess is that 100,000 to 200,000 need independent living services. If those federal policies are zeroing in a specific direction and are not in the best interest of deaf people or do not provide enough flexibility so deaf persons can receive effective services, then we are guilty of a disservice to that population. Independent living services for deaf persons must be delivered through training. The handicapping aspects of deafness do respond to training. I hope you people will help us in this matter and spread the understanding that wherever independent living services are established we must also have intelligent and effective service delivery to the 100,000+ deaf people who need that service. This means that independent living centers, in order to provide intelligent and effective service delivery, must have a core staff of experts interested in serving low functioning deaf people.

# NARRTC Awards

## In Acceptance

**Honorable Jennings Randolph (D-WV)**

*The National Association of Rehabilitation Research and Training Centers chose two outstanding leaders in the field of rehabilitation to honor at its Fourth Annual Conference. Engraved plaques were presented on behalf of the Research and Training Centers to the Honorable Jennings Randolph and to Dr. William A. Spencer by Dr. Margaret Giannini, Director, NIHR, and Dr. Joseph B. Moriarty, President, NARRTC.*

President Joseph Moriarty, President-Elect John Goldschmidt, and members of the National Association of Rehabilitation Research and Training Centers, it is a great joy to be here. I am honored to accept this award from your organization.

In our Senate Subcommittee on the Handicapped I have been privileged to work with you for many years towards our mutual goal of bringing about a social, economic and physical environment in this Nation that will enable each handicapped person to achieve his or her personal potential. There is yet a long way to travel to achieve this goal—but we have made progress. I know you will agree with me that the future holds great promise for disabled people. All of us here share a belief in the importance of research in improving the quality of life for this major sector of our population. There is a common concern, too, in solving the problems faced by research programs today: the need for funding and the need for focus.

Last Fall I had the honor of cosponsoring, with Chairman George Brown of the House Subcommittee on Science, Research and Technology, a series of workshops to inform members of Congress and their staffs of the "state-of-the-art" on technology as it relates to handicapped persons. This endeavor was part of an overall attempt to bring together information about the great potential for broader utilization of this Nation's vast scientific and technological resources in addressing the problems of handicapped individuals. These proceedings are now in print, and I am sure they will be useful to persons concerned with rehabilitation technology. I am hopeful they will prove to be a valuable base of information for members of Congress in future deliberations concerning the decisions they will make on appropriations for research and training programs to benefit handicapped persons.

We need to bring to public awareness not only what can be done in the field of rehabilitation research, but also what has already been done. Too many people are unaware of the accomplishments of Rehabilitation Research and Training Centers during the last decade, despite a decrease in funding in real dollars. You who have actively participated in these accomplishments know firsthand of the remarkable difference they make to the lives of handicapped individuals, of the increased opportunities opened up to them; and you know also of the resulting benefits that accrue to the Nation as a whole.

Unfortunately, as we all know, monies appropriated for research are often painfully visible to the American taxpayer while monies not required because of research are never counted or brought to mind. It has been suggested to me that Congress should appropriate each year the amount of money which it would have had to spend had it not been for the research supported in previous years; that this amount should then be returned to the American public so that people would be more aware of the long-term benefits of research. Obviously, that is not going to happen, but it does illustrate the great need for making the public more aware of the cost/benefit ratio of rehabilitation research.

Included in the 1978 Amendments to the Rehabilitation Act—Public Law 95-602—were major new research authorities. I share your concern, as voiced in testimony before the Subcommittee on the Handicapped in November of 1979, over the lack of efforts to implement these new authorities. There have been some improvements in the situation since then: the Director of the National Institute of Handicapped Research has been appointed, the new Secretary of Education has appointed many of the persons to serve under her, and members of the National Council on the Handicapped have been named.

Although the staffing problem has improved, the money problem has not. Clearly, money will be tight in coming years as taxpayers continue to question the need for federal spending. There is serious concern for the future of research and development programs. That is not to question the value of such programs, but merely a warning that the value must be clearly documented and demonstrated and made readily understandable to the American public. Both the National Institute of Handicapped Research and the National Council on the Handicapped will play key roles in any future appropriations for programs to serve handicapped areas. If these two agencies play their roles effectively, and we continue our efforts, I am confident that the people of our Nation will respond in a positive fashion to a demonstrated need and a demonstrated benefit.

Again, this award you have given me has a double meaning because it is presented by my good friend and fellow West Virginian, Joe Moriarty. The West Virginia Research and Training Center has flourished under his leadership and his tenure as president of the National Association of Rehabilitation Research and Training Centers has been a distinguished one. I am confident his future contributions to opportunities for our handicapped citizens will be as significant as they have been in the past.

**Opposite page:**

**Honorable Jennings Randolph (D-WV)**
**Chairman, Subcommittee on the Handicapped, Committee on Labor and Human Resources**
**U.S. Senate**

# In Acceptance

**William A. Spencer, M.D.**
**President, The Institute for Rehabilitation and Research, Houston, Texas**
**Director, Medical Rehabilitation R&T Center**
**Baylor College of Medicine**

*". . . Truly, we could not have honored a giant taller than Bill Spencer, not only as a professional, not only as a humanitarian, and not only as a husband and a father, but as the wonderful man he is."*
*Dr. Margaret Giannini*

I am immensely pleased to have this chance through your honoring me to tell each and every one of you the pleasure that I have experienced in knowing you, in working with and for you, in sensing your values and commitments and in your sharing the challenges of our new Research Institute. Many of the successes you attribute to me are due to my own associates in Houston, who fortunately, often offset my own shortcomings and my prolonged absence.

Most importantly, I have come to realize that together the beliefs and the knowledge gleaned in the last three decades in the area of providing a foundation for a major research effort on behalf of the disabled person are finally beginning to become a reality. I wanted to have this opportunity to personally tell Senator Jennings Randolph that this reality has followed upon the leadership and the support that has been shown by the Senator, his associates, and also his colleagues, not only in the Senate but also in the House . . . . notably John Brademas, Olin Teague, and many others. The inspiration and the guidance of Mary Switzer and others who preceded her and now succeed her shall now be recognized. These goals have been most recently, strongly affirmed by the President of the United States. I hope that you are truly proud of what you have helped to create.

As I reflect upon my own experience in this field, which many in this audience nurtured and developed and will continue to do so, one fundamental concept has emerged; it is the notion of inclusion of a person with handicaps as a full-fledged member of his or her community, having the rights and assuming those responsibilities which make our increasing dependence upon one another possible in daily life. As such persons search for autonomy, they are simply mirrors of any one of us in our own particular pursuit of both meaning and value to our span of life, whatever the duration. Whether he or she is an elderly person who regains the dignity that has been earned by a life of value or a child facing the opportunity to enter it, whether survival is only months or

decades, it means a great deal to the person and his family. By recognizing and bringing into reality the rights of the handicapped person to be included in a fully active life, we thus contribute to social justice and also accept the right to be different! Such goals constitute one of the highest aspirations of mankind today the world over, and I think they will likely endure far beyond any of us.

I had the opportunity to see a plaque on the wall at the Georgia Warm Springs Foundation which has a fitting quote from an undelivered speech of Franklin Delano Roosevelt just before he died. It was: "The only barriers to overcome in meeting the challenges of the future are the doubts of today. It is to have faith and commitment to realize (them) tomorrow." We are facing together that tomorrow. We are being joined by the persons we have assisted in this quest, we cannot fail!

*Inscription on Plaque:*

*The National Association of Rehabilitation Research and Training Centers presents its distinguished colleague award to Dr. William A. Spencer, M.D., for his untiring efforts on behalf of research and training centers and for his decisive leadership in the establishment of the National Institute of Handicapped Research.*

**Dr. Margaret Giannini presents a tribute to Dr. William Spencer.**

# Proposed NIHR Federal Regulations Relating to RTCs

**Moderator - Neal D. Little, Ed.D.**
**Associate Project Director**
**University of Arkansas**
**Vocational R&T Center**

**Nathan Ed Acree**
**National Institute of Handicapped Research**
**Washington, DC**

*The purpose of this conference session was twofold: (1) to bring an updated report on the status of the NIHR proposed federal regulations with particular emphasis on those which pertain to the RT Centers, and (2) to give members of the NARRTC an opportunity to have direct input into the formulation of the final official regulations which will govern RTC operations in the future.*

*Principals in the development and drafting of the proposed regulations were Nathan Ed Acree, who has coordinated the development of regulations relating to the total of NIHR, and Dr. Joseph Fenton and Emily Cromar, who have been responsible for drafting regulations pertaining specifically to the RT Centers.*

*The preparation of these proposed regulations was precipitated by the enactment of P.L. 95-602 which, among other things, created the National Institute of Handicapped Research, and by the enactment of P.L. 96-98 establishing a new Department of Education within which NIHR is now housed. It is necessary, therefore, that the NIHR proposed federal regulations be consistent with broader regulations referred to as EDGAR, the Education Division General Administrative Regulations, which were published on April 3, 1980.*

**Opposite page: (left to right) Ed Acree, NIHR; Dr. Neal Little, University of Arkansas R&T Center; and Emily Cromar, NIHR address the assembly concerning proposed NIHR federal regulations.**

## NIHR Proposed Regulations Overview (Capsule Summary)

This one-hour overview of the history and approach used in drafting the proposed federal regulations for the National Institute of Handicapped Research highlighted the scope of input provided from various federal agencies and organizations; the role of the new Department of Education in the outline of regulations; the format for proposals as outlined in the Education Division General Administrative Regulations (EDGAR); and the purpose of federal regulation, which is essentially to explain in a clear and succinct manner the application process for securing federal assistance or benefits including the method by which selection is handled. It was noted early that all regulations first appear as proposed rules in draft form with a period of 30 to 120 days established for comment.

Information was provided on the need for renumbering and republication of EDGAR to be tailored specifically for the Department of Education, emphasizing that much of the content material would remain the same. Present subparts of EDGAR were reviewed noting that Subpart B includes a description of the NIHR and Subpart D relates to selection of criteria used by peer review groups. Conflict of interest, proposed group peer review by non-feds, and selection criteria were reviewed in respect to Subpart D. It was further noted that Subpart E stipulates the conditions which must be met by grantees (i.e., regional advisory councils, allowable costs and indirect cost rates).

Considerable attention was devoted to the area of "definitions" related to disability, noting that the NIHR favors adoption of a broad definition such as that prescribed in Title IV for the National Council which states that a handicapped person is one with a physical or mental impairment. Here the word "impairment" replaces "disability" and refers to a condition which limits the person in one or more major life activities. In applying the term impairment to the proposed regulations, the term is further defined through a logical progression from the lowest level of disability or deficit, through handicapping conditions, and finally to independence as essentially defined by the Independent Living Research Utilization Project at TIRR, Houston.

Although originally scheduled for completion and review on April 15, 1980 the proposed regulations have been detained in the review process and were not yet published on the date of this presentation.

# Proposed Federal Regulations: Rehabilitation Research and Training Centers

**Emily Cromar**
**National Institute of Handicapped Research**
**Washington, DC**

*The R&T Center regulations were still in draft form and were offered for information and input. All input which conference participants wished to provide was welcomed. The regulations are intended to standardize the rules of the R&T Center grant program to the maximum extent possible and to provide general information on how to apply for a research and training grant; how grants are made; and the general conditions that apply to a grant. The regulations contain the following sections which address particular aspects of the R&T Center Program.*

**Activities eligible for assistance**

Grants pursuant to this Part will be provided to pay part or all of the costs for the establishment and support of Rehabilitation Research and Training Centers to be operated in collaboration with institutions of higher education for the purpose of:

(a) Conducting coordinated and advanced programs of research in rehabilitation and to widely disseminate and actively promote the utilization of findings resulting from research thereby reducing the delay between the discovery of new knowledge and its application in practice; and

(b) Conducting training programs (including graduate training) to assist individuals to more effectively provide rehabilitation services and to provide training (including graduate training) for rehabilitation research and other rehabilitation personnel.

**Types of activities authorized**

(a) The research to be conducted at each Center shall be determined on the basis of the particular needs of handicapped individuals by utilizing the geographic area served by the Center as one source for identifying those problems which are national in scope. It may include basic research, where related to identifiable rehabilitation techniques or service or applied medical rehabilitation research, research regarding the psychological and social aspects of rehabilitation, and research related to vocational rehabilitation. The Center shall develop practical application for the findings of its research.

Each separate study or investigation shall have a reasonable relationship to a central topic or research core area and shall contribute cumulatively to a coherent body of knowledge for the resolution of rehabilitation problems.

(b) Training programs at a Center shall endeavor to: widely disseminate and actively promote utilization of new knowledge resulting from research; incorporate rehabilitation education into all rehabilitation related university undergraduate and graduate curricula; provide short-term, in-service and continuing education to improve the skills of professionals, paraprofessionals, consumers, parents, and other personnel involved in rehabilitation as related to new knowledge generated through research findings.

(c) The service program components shall be developed to achieve the integration of services, research and training necessary to: provide the direct knowledge and awareness of the needs of disabled persons; provide the linkage and structure to enable a Center to more adequately and realistically assess these needs and to provide a laboratory for the development, testing, implementation and demonstration of methods, techniques, procedures, systems, etc., to respond to the needs. Grants may include funds for services rendered by the Center in connection with research and training activities.

(d) The three major activities—research, training, and services—are expected to be mutually supportive. Specifically, this concept calls for research needs to derive from service delivery problems; for research results to be assessed and applied in service delivery settings; and for research results to be disseminated through training.

**Areas of problems that may be researched**

Research funded under this Part shall develop and demonstrate the most effective methods and techniques for rehabilitating disabled persons.

**Application procedures**

An eligible applicant who wants to apply shall meet the application requirements of the Education Division General Administrative Regulations (EDGAR) in 45 CFR Part 100a (Direct Service Programs) and Part 100c (Definitions) with the exceptions noted in Part 1364.3 above.

**Selection criteria used in this program for Center applications**

Grant applications will be reviewed and evaluated against the following criteria:

**(a) National Need**

1. The extent to which the applicant reflects knowledge of and has analyzed rehabilitation needs with specific references to persons or agencies to be served or benefited.

2. The extent to which the applicant exhibits thorough knowledge of pertinent previous research and relates the proposed research to it.

**(b) Plan of Operation**

1. The soundness of the proposed plan of operation including considerations of the extent to which the objectives are clearly described; are capable of being attained; and are measureable.

2. Evidence of a sound administrative structure and organizational mechanism for implementing and operating a Center.

3. Evidence of support from rehabilitation agencies, from public and voluntary organizations, and specific measures described for achieving a high level of interaction between the Center and these resources in implementing and operating the Center.

4. A description of an Advisory Council to be used in the development and operation of the Center and types of constituents to be represented.

5. The extent to which the applicant demonstrates that the Center research will be effectively utilized and will directly improve the affiliated services and will likely be effectively utilized by other programs for similar purposes.

6. The extent of provisions made for research dissemination.

7. The applicant's plan for programmatic research within research core areas.

8. The quality of proposed individual research and training projects.

9. The extent of the proposed relationship between the research and training projects and the identified research core areas.

10. Evidence that the training projects will be in consonance with and capable of achieving training objectives.

**(c) Evaluation Plan**

1. Provisions are made for adequate evaluation of the effectiveness of the Center program and for determining the extent to which objectives are accomplished.

**(d) Adequacy of Resources**

1. The extent to which the university with which the Center is affiliated has multidisciplinary rehabilitation resources available that will insure a sound and substantial growth of a significant Research and Training Center.

2. The extent to which the Center can draw upon and coordinate the resources and staff efforts of the university and the clinical/service component to accomplish its objectives.

3. The adequacy of the facilities and resources available to the Center to conduct the proposed work.

**(e) Budget and Cost Effectiveness**

1. The extent to which the budget reflects the activities and the reasonableness of the allocation of the resources among the activities.

2. The costs of the program are reasonable to the government in relation to expected benefits.

3. The extent of outside support and services.

**(f) Quality of Key Personnel**

1. Project personnel, actual or proposed, are highly qualified and appointments of core staff are appropriate.

**Matching Requirements**

While no specific percentage of grantee sharing is required, grantees are expected to commit their resources to the support of activities of the Center. The amount of participation will be determined at the time of the award.

**Length of Center support.**

The initial application may be proposed for up to a five year duration. Applications for centers proposing multi-year projects must be accompanied by an explanation of the need for multi-year support, a review of the objectives and activities proposed, and budget estimates to obtain the objectives in any proposed subsequent year. If an application demonstrates, to the Director's satisfaction, that multi-year support is needed to carry out the proposed projects, the Director may, in the initial notification of grant award for the Center (which shall be for up to a twelve month period) indicate an intention to assist the Center on an appropriate multi-year basis through continuation grants and subject to availability of funds. Continuation awards will be reviewed annually on a non-competitive basis and approved for continuation only if:

(a) Funds are available to continue the Center;

(b) Satisfactory progress has been made in implementing the approved work plan in achieving the Center goals and objectives as indicated by site visits, progress reports and other relevant data.

**Purpose and role of Advisory Council**

**(a) Purpose**

To insure maximum research responsiveness to rehabilitation needs, an Advisory Council shall be established to function as an integral part of the operational structure of a Research and Training Center. Composed of representatives from rehabilitation related public and voluntary agencies, labor and industry and consumers, including a representative from RSA Regional Office staff, the Council shall establish and maintain linkages between the Center and the rehabilitation needs of disabled persons.

**(b) Role**

The Council's role is to assist in identifying research and training priorities and to transmit to all concerned the innovative concepts and techniques that are engendered by the Center's research and training activities.

**(c) Authority**

The functions of the Advisory Council shall be advisory in regard to all aspects of the Center's program and functions.

# NIHR Long Range Planning

## Introduction

**Moderator - Robert P. Jacobs, M.D.**
**Director of Research**
**The George Washington University**
**R&T Center**

We have all been participating in the culmination of many discussions on the new Institute and how the R&T Centers themselves can input into long-range planning. We would like to continue this discussion during this next hour, focusing on some of the other programs in the Institute and their long-range plans. Mr. Dick LeClair will initially discuss an overview of the planning process and then, in the absence of Mr. George Engstrom who could not be with us today, will also discuss the topic listed for Mr. Engstrom, Dissemination and Utilization Plan for the NIHR.

Mr. LeClaire will be followed by Mr. Ed Acree who will discuss Management and Project Research, Mr. Paul Thomas, Medical Project Research, Dr. Tom Finch, Technology Research for the Handicapped, Dr. Lee Coleman, Psychosocial Projects, and Dr. Martin E. McCavitt, the International Program Research Plan.

**Panel members representing the National Institute of Handicapped Research discuss the Long Range Plan.**

## Overview of the Planning Process and Plans

**Dick LeClair**
**National Institute of Handicapped Research**
**Washington, DC**

Since February 1980, the NIHR Long Range Plan has been rapidly developed under the leadership of the Director of the Institute, Dr. Margaret J. Giannini.

In developing this long range plan, NIHR made a major effort to involve handicapped individuals, voluntary organizations serving their needs, and Federal and State agencies sharing responsibilities or interests in improving the quality of life for handicapped persons. Twelve task forces consisting of representatives of 30 public agencies and an equal number of representatives from the voluntary sector were organized to participate in the planning process. These task forces considered needs and possible research approaches applicable to the following topical areas: (1) Vocational/Educational, (2) Technology for the benefit of handicapped individuals, (3) Rehabilitation medicine, (4) Mental retardation and developmental disabilities, (5) Mental illness, (6) Speech and hearing impairments, (7) Visual impairments, (8) Delivery of services and impact of disability, (9) Psycho-social aspects of disability, (10) International aspects, (11) Research utilization and dissemination of findings, and (12) Independent Living.

Each task force was required to base its recommendations for future research approaches upon needs that could be validated on the basis of their potential for effecting improvements in the lives of handicapped individuals. Appropriate documentation was required, such as that available from the White House Conference on Handicapped Individuals or other reliable sources. In addition, suggestions were requested from approximately 3,000 voluntary organizations, rehabilitation facilities and individuals known to have expertise with respect to problems affecting handicapped individuals.

Responses from 111 agencies and individuals were received and analyzed, and as a result many useful suggestions were incorporated in the Long Range Plan. Some of these responses were particularly helpful in the development of research priorities and approaches within NIHR.

The Research and Training Centers have been extremely responsive to the development of the Long Range Plan and major segments have been received from the medical, vocational, mental retardation, mental illness, blindness, and deafness centers. These materials are now being integrated into a single cohesive document which will represent the Research and Training Centers' portion of the Plan.

Similar sections are being prepared by the Rehabilitation Engineering Centers and by the Discrete Grant Program for inclusion in the overall planning document.

By the end of May we hope to have a draft of the entire Plan at which time it is our hope that this Association will designate a select number of representatives to review the draft document.

I know that Dr. Giannini joins me in expressing our sincere appreciation for the invaluable assistance that you provided in developing this very significant planning document.

# Management Project Research Plan

**Nathan Ed Acree**
**National Institute of Handicapped Research**
**Washington, DC**

I am primarily a generalist, having been a rehab counselor way back, and so I started on that part of the Plan for which I had responsibility from the perspective of a generalist. But before getting underway I realized I had been given an assignment relating to more than management. Dick (LeClaire) had given me a goal and four objectives, all of which needed to be worked into the Plan. The general goal was to conduct a comprehensive research and demonstration program to improve the economic status and all aspects of the service delivery system impacting on handicapped individuals. The four objectives directed at this goal were (1) to document the economic impact of disability and develop ways to reverse any negative trends, (2) to identify and utilize the most effective management and administrative practices, (3) to determine current problems with the service delivery systems and identify techniques for improving the quality of service, and (4) to examine the current methods for formulating policy and determine alternatives.

I had a very interesting group of individuals to work with. Dale Hanks and Charlie Weston from the West Virginia DVR provided the down-to-earth reality needed to insure that what was proposed was something needed. Jerry Lorenz and Stan Smits representing the NRA Division of Management provided the management viewpoint. Don Harrison from the University of Michigan Regional Rehabilitation Research Institute in program evaluation provided that viewpoint. Will Massie, Dick Mella, and Mike Dolnick provided viewpoints from RSA.

After working two days on a number of problems we identified in these areas, our group developed a number of recommendations as input into the NIHR Long-Range Plan, among which were:

- Give top priority to the term "economic impact of disability" through ongoing activities like those of the University of Chicago involving a series of demonstrations around the country which look at handicapped individuals in the SSA system (or who may eventually be there). Examine the service delivery system to which these persons are exposed and develop alternative ways to get these persons back into the labor market before they get into the system. Reverse the trend and in the long-run it will cut down on costs, but more importantly it will have a positive effect on the quality of life for these people.
- Look at the unemployment rate and its impact on handicapped individuals. When unemployment goes up, generally handicapped individuals begin to lose their jobs first.
- Study the relationship of the consumer price index on the real dollar support for the rehabilitation program to determine what is happening within the Federal-State program.
- Examine what business and industry are doing in the area of improved management strategies to determine which techniques could be adapted or modified for use in rehabilitation.
- Continue efforts in program evaluation, such as those done at the University of Michigan RRRI, with an emphasis on how the state director should approach cutback management with the leveling off of appropriations and increased inflation and salaries.
- Develop more information on Similar Benefits.
- Conduct research on a new role for state rehab agencies in becoming advocates for handicapped individuals as opposed to concentrating on simply a Status 26.
- Study demographic data collected by the Institute to determine the reasons for unsuccessful closures.
- Conduct more research in consumer involvement. Build on the work of the Oklahoma telecommunications project and the work which has been supported with the American Coalition of Citizens with Disabilities.
- Continue research efforts into the problem of reducing counselor paperwork, similar to the Georgia Management Project, to permit counselors to have more time with clients.
- Establish a "think tank" to do forecasting work related to policy alternatives which will affect the entire program five to ten years from now.

The above are just a few of the highlights which are presented in the more comprehensive plan which was developed by the management group.

# Medical Project Research Plan

**J. Paul Thomas**
**National Institute of Handicapped Research**
**Washington, DC**

The medical research program of the NIHR, we believe strongly, requires considerably more breadth, scope and responsiveness to effectively do what is needed in the physical restoration, functional appraisal, and improved physical capacity areas. When the Institute was formed and Dr. Giannini said, "We want to do the Plan and we want it now," I did not view that as an ominous experience at all. We saw it as a marvelous opportunity to collect our thoughts and to really be able to say what we had been wanting to say over the past several years. Interestingly enough, just a few minutes before our presentation here this morning, Dr. John Goldschmidt presented to me the medical R&T Centers' input for the medical rehabilitation/physical restoration section. After scanning it briefly I am delighted to tell you that the medical research plan for the Institute and what the medical R&T Centers came up with is almost identical material, issues, and areas of investigation. Let me elaborate for you.

There are two research areas in the Institute's legislation that automatically had to be dealt with and these are under section 204(b). Within a list of twelve items, item (b) (3) is clinical spinal cord injury research and (b) (4) is end-stage renal disease research. We naturally have had to include these in our medical research plan, and research in these areas will be heightened because of the Congressional interest.

In addressing other areas that need to have emphasis in medical rehabilitation, we thought it only fair to prepare something broad enough to permit us to do what was needed and also permit our many medical specialty interests to be represented. Therefore, the first part of the medical R&D Plan is a rather lengthy discussion of issues, problems and priorities based on the process of rehabilitation which I find, as I look at the product from the medical R&T Centers, is exactly what our medical consultants suggested.

We in the medical R&D program have believed for a long time that there is "the disability of the hour" and that with a heightened visibility and push, researchers, clinicians, and advocacy groups get interested and suddenly positive things begin to happen. Therefore, there are several categorical disabilities, aside from spinal cord and ESRD, on which we have specifically focused in the medical R&D Plan. These include:

**Cardiovascular Disease**

In this area we looked at previous research; at specific plans such as that developed by the Rehabilitation Committee of the National Institute of Heart, Lung, and Blood Diseases; and also at some of the work that other outside consultants have done.

**Burn Rehabilitation Research**

This is an area that we have believed in for a long time and that the rehabilitation community has not properly addressed. Two initial baseline studies are underway now which we wish to expand much more broadly. We have looked at the research that has been done nationally and internationally and have sought top outside consultants in the field to tell us where they think NIHR ought to be going in this area. The Plan reflects some very innovative and necessary research in burn rehabilitation.

**Severe Head Trauma**

We learned that in our spinal injury program, the neurosurgeons were observing the incidence of patients requiring rehabilitation from traumatic head injury is four or five times that of spinal injury. We did not find any agency doing much about head trauma rehabilitation research here in Washington, nor did we see much happening with head trauma in the State-Federal rehabilitation program. We have initiated two definitive, collaborative baseline studies which are currently underway and which will serve to provide future research directions.

**Multiple Sclerosis (including other neuromuscular diseases)**

This area has not really been addressed in the past, but we feel it is timely. The national statistics, economics of the problem, and other issues at hand really require us to address MS. Through national organizations such as the National MS Society and their medical advisory groups, through research that is being done in the field, and through outside consultants we feel we have a fairly solid plan here.

**Chronic Obstructive Pulmonary Disease**

Again, through scientific and clinical literature review by staff and consultants, this being the second highest area of social security disability payment, we must address this area strongly and determine what can be done across the whole board from prevention through health maintenance.

## Dissemination and Utilization Project Plan

**Arthritis and Related Rheumatoid Processes**

Good input has been received from national organizations, the National Arthritis Foundation, from researchers, and from the National Plan of the Arthritis and Metabolic Diseases Institute. This will open the doorway to get things started.

A May 1, 1980 Federal Register announcement was developed, and there are three areas that I have already mentioned that are included in this announcement. I would like to close by highlighting these areas.

**Spinal Cord Injury**

"To generate new knowledge leading to the development of innovative and improved techniques of medical management of spinal cord dysfunction, with emphasis upon the newly-disabled patient in the acute medical care phase. Priority will be given to those projects that focus upon experimental and evaluative modalities for determination of functional potential, the clinical course including patho-physiology of early developing complications, and new techniques for the prevention and treatment of such complications as they affect readiness for rehabilitation . . ."

**Multiple Sclerosis**

"To seek new knowledge to the heightened understanding of the cause, duration, and severity of the exacerbation of the multiple sclerosis course as it affects potential for rehabilitation . . ."

**End-Stage Renal Disease Research**

"To develop new knowledge through scientific investigations that lead to the improvement of end-stage renal disease rehabilitation services. Priority will be given to those investigations that emphasize home and other forms of dialysis methods including parientenile, ambulatory and innovative hemodialysis techniques."

The medical research program continues to deliver some excellent results. With Dr. Giannini's fine support, we have been able to reflect some of the early work for the Plan in the Federal Register announcement. Now that we have seen the medical R&T Centers' input into the Plan, I feel we have excellent congruence—something that we can collaboratively move with to broaden our total medical R&D effort into a really significant program in the future.

**George Engstrom**
**National Institute of Handicapped Research**
**Washington, DC**

*In Mr. Engstrom's absence, the Dissemination and Utilization Project Plan was summarized briefly as follows by Mr. Dick LeClaire.*

In the 1978 Amendments to the Rehabilitation Act of 1973, research dissemination and utilization is stressed repeatedly. The results of research must be utilized, and NIHR is strongly committed to achieving this goal.

One aspect will be to encourage R&T Centers to continue to do and expand upon the fine work that is being done, such as the **INFORMER,** the seminars, workshops, and the large number of RTC publications. Centers will be encouraged to intensify their efforts in utilizing the results with emphasis on demonstrating the research techniques and other findings that are generated by the research program. Training will also have an increasing significance as a mechanism to prompt results.

Secondly, there will be a substantial effort devoted to utilization at the NIHR central office itself. An expanded information dissemination program is in the planning stages and will involve R&T, REC and discrete grants programs. Specialized workshops in key areas will be sponsored periodically with other Federal agencies. Rehab Briefs and state-of-the-art documents will be prepared on major findings resulting from our research activities. A program of selected demonstrations is also planned to demonstrate and evaluate new techniques developed by various research programs within NIHR.

Finally, every effort will be made to encourage the private sector to develop, produce and market aids and devices which are initiated by R&T and REC Centers as part of their research programs.

These are only a few examples of types of activities that NIHR hopes to promote in order to ensure that the results of research are made known to everyone concerned and fully utilized to benefit the habilitation and rehabilitation community.

# Technology for the Handicapped Research Plan

**Dr. Tom Finch**
**National Institute of Handicapped Research**
**Washington, DC**

The process that was followed within rehabilitation engineering is a little different perhaps than some of you have previously heard. After looking at the Amendments to the Rehabilitation Act, our group decided that rather than plan categorically as we have done in the past, we would try to establish how we might approach the problem differently. From this it was recognized that there are primarily three areas which need to be addressed: needs assessment, needs addressment, and service delivery. Rather than referring to topics in terms of core areas of research, as we have in the past, we decided to look at the problem from a functional perspective because the legislation states that we should be concerned about the problems of handicapped individuals, primarily severely handicapped individuals.

Within the area of needs assessment, we then identified several different topics on which we are developing research issues. These particular areas will be prioritized later on in the planning process and are not listed in any particular order of significance at this time. Several areas of focus are associated with each one of these functional categories:

**Mobility**
Locomotion, wheelchairs, personal licensed vehicles and public transportation

**Housing**
Accessibility, architectural barrier removal, and appropriate fixtures and furniture

**Communication**
Reception and expression of information including inter-personal communications, telecommunications, and access to stored information

**Functional or Physical Restoration**
Orthotics and prosthetics, functional electrical stimulation, tissue mechanics, biomechanics, surgical procedures and equipment, sensory stimulation substitutes, and diagnostics

**Education**
Specialized equipment and training for those who are going to be providing the services to our client

**Recreation**
Physical education

**Activities of Daily Living**
Environmental control systems, medical self-care, feeding devices, and hygiene devices

We next asked ourselves, "If these are functional categories, who will be the providers of care and who is going to assist us in the development of the plan?" We then turned our attention not only to our representatives from the rehab engineering center community, but also pulled together an informal interagency committee including representatives from the National Science Foundation, the Veterans Administration, the Bureau of Education for the Handicapped (now known as the Office of Special Education), the Departments of Transportation and Housing and Urban Development, and basically all Federal programs that sponsor handicapped research in some way or another. These people came to agree on the categories just identified for you.

The next step in the process was essentially to ferret out all the information from these particular agencies that had to deal with technology and research in these particular categories. An effort was made to pull from the committee all research plans—past, present and future—and coordinate those and come to some agreement as to what NIHR could do in the area of technology research. From that, we are in the process now of identifying specific priority areas of research that will be presented in the plan.

Who else is concerned in terms of the needs assessment and needs addressment areas? Our plan identifies the opportunity for handicapped individuals and families to participate in the development of technology, as well as organizations representing handicapped persons, practitioners (other than those in the rehab engineering community), administrators for the State and Federal levels, manufacturers and distributors, authorizers and providers (third party payers), and other researchers from the medical/social/psychological community, etc.

Our particular concern, which is also voiced in one of the purposes of the Amendments to the Rehab Act, is to sponsor and to support research in the areas of stimulation, production, distribution and marketing of devices and technology to aid the severely handicapped client. This is an area that has long been talked about. There is a recognized need to continue to get into this area, but we have not conducted any research on this particular subject. For the first time, we have built in an opportunity to work with private industry and for private industry to work along with

us in the development of a technology plan specifically aimed at the stimulation, production and distribution of equipment.

Concomitant with that is also a plan to develop certain evaluation centers or an evaluation component within technology that will allow us not only to evaluate that material developed by the rehab engineering community but also to evaluate devices and technology developed within the private sector. We have now envisioned a two-way street where some of the products developed within the engineering community will be sent to private industry for evaluation, and rehab will in turn receive technological devices from private industry which they feel can meet the needs of severely handicapped persons. We will be able to do this for the first time primarily because of the Amendments to the Rehab Act.

We in the planning process also envision a Technology Advisory Committee where representatives from the private sector and from universities can sit in, share with us, and review the devices we are in the process of developing.

After several meetings, over the last nine months, with our interagency committee and representatives from the rehab engineering community, as well as representatives from State and Federal offices, the plan now is out for review and comments from all sectors. From this response we anticipate being able to prioritize categories within the array previously listed and identify priorities within each of those categories. The plan will then be submitted to Dr. Giannini who in turn will submit it to the National Council.

**Dr. Lee Coleman**
**National Institute of Handicapped Research**
**Washington, DC**

## Psychosocial Project Research Plan

What I will do, as most of us have, is describe the process that we went through and then, in effect, read an outline. Although probably only a small percent of this total 60-page report will be included in the final NIHR Plan, I feel it is a document which can be used for the future in terms of ongoing planning.

In accomplishing this task I had three main concerns: (1) to reduce this task to some workable, manageable job; (2) to try to avoid duplication by determining what the R&T Centers were including in their plans since a very heavy percentage of what you do comes under a definition of psychosocial; and (3) getting a plan done on short notice. Initially I searched for parts that could be eliminated. Fortunately, the R&T Centers had taken over planning in the areas of mental retardation, developmental disabilities and mental health, areas which represent a very large part of what is traditionally considered within the psychosocial area. We will use what the RTCs have proposed in these areas. Unfortunately, we were working on parallel tracks and the RTC material was not ready at that early date, so I assume that there is redundancy which will have to be eliminated.

With Roberta Sadler's assistance we worked from whatever existing documents were available and benefited very much from exposure to my former office roommate who was in charge of telecommunications, as most of the work was done on the telephone. We took existing needs assessments, got on the telephone and initiated an almost endless chain of communication, bouncing ideas off people and getting their responses. We then organized the existing material and parceled it out in sections for people to fill in missing strategies. When all the materials were returned, Roberta and I did the compilation.

The document covers quite a bit of territory in the psychosocial area, and from looking at what has been done over the years it seems that this area, at least as far as the Discretionary Grant Program is concerned, has not been researched extensively. Therefore, we tried to add emphasis to an area which we felt was extremely important. Most of the research and much of the service that has been done in the field of rehabilitation has concentrated on the physical dimension of disability, and yet we have discovered over the years that there are still many physically disabled individuals who do not succeed

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through the rehabilitation process or do not make adequate adjustments to living in the community. Much of this lack of actualization of their potential is attributable to problems in the psychosocial area.

Obviously, we had to start by defining psychosocial. We proposed that psychosocial factors refer to the matrix of personal variables (i.e., personality, emotionality, cognition, attitude, behavior) and the social variables (i.e., attitudes of family, friends, employers, teachers, etc.) and how they affect each other or interact in relation to handicapping conditions. We felt that these factors can be a function of the disability itself and/or contributors to the adaptive process of the handicapped individual. In fact, the psychosocial problems of the disabled, we felt, were often much more debilitating than the actual physical or cognitive limitations to the extent that they act as barriers in keeping a disabled individual from the mainstream of society.

We looked at the whole area of psychosocial and broke it into essentially three different categories: psychosocial environments, rehabilitation processes and outcomes, and personal adjustment to handicaps, disability, and severe chronic illness. A definition, a statement of overall need, a description of the problems and background, specific strategies, and specific objectives were developed for each of the three categories. I will describe the categories and list the sub-areas under each:

**Psychosocial Environments** - investigations that pertain to the characteristics and influence of the psychological and social environments in which the disabled individual lives, including:

- Improving the social environment
- Expansion and integration of rehabilitation gains into social and vocational functioning
- The relationship of handicapped individuals to employers and educational institutions
- The involvement of consumers, advocates, and self-help groups

**Rehabilitation Processes and Outcomes** - studies of the psychological influence of a broadly conceived rehabilitation process, from primary medical care through reintegration into society, and of the various factors that affect the outcome including:

- Interaction of the client, the professional, and the environment in the rehabilitation setting
- Psychosocial aspects of rehabilitation engineering
- Effects of handicapping conditions on learning
- Predictive measures of adjustment
- Assessment of psychosocial functioning in relation to rehabilitation potential
- Psychosocial factors in the relationship of the health-care and rehabilitation professional to handicapped individuals
- The relationship of mental health professionals to handicapped individuals

**Personal Adjustment to Handicapped Disability in Severe Chronic Illness** - investigations focusing on the disabled individual's personal adjustment, including:

- The natural course of and reaction and adjustment to disability
- Psychosocial development
- Remediation of negative self perception
- Psychosocial variables of motivation
- Locus of control
- Psychological coping mechanisms of the rehabilitant

# International Program Research Plan

**Dr. Martin E. McCavitt**
**National Institute of Handicapped Research**
**Washington, DC**

The International Program within NIHR and its predecessor agencies, RSA and SRS, is not new. It really goes back for some 30 years to the time when we were involved in technical assistance and training. This was followed, of course, by involvement with the United Nations and its specialized agencies where this program has been providing assistance and working on resolutions and special position papers, documenting U.S. concerns in the area of rehabilitation. In fact, I should point to the fact that it is now the beginning of the International Year of Disabled Persons - 1981, which is, in a sense, an outcome of those earlier efforts. Our 1981 involvement internationally should certainly be significant.

As long as eighteen years ago the International Program was involved in the publication of books, one of which described rehabilitation in 37 countries, and later in 1964 highlighted rehabilitation of the disabled in 51 countries.

We are celebrating the 20th anniversary of Public Law 480 this year, whereby thirteen countries have elected to be a part of a coordinated and cooperative effort. Not only the Department of Health, Education, and Welfare, certainly including rehabilitation, but many other agencies within the government have participated.

Public Law 480, the Special Foreign Currency Program, was followed by another important law, Public Law 86-610, which is the International Health Research Act, authorizing programs for fellowships, seminars, and consultations. This was probably the real backbone of our International Program because it made it possible for U.S. researchers, scientists, and specialists to go abroad and participate in and give guidance to research under Public Law 480. In turn, this country invited a number of scientists to come this way. In fact, we have been involved with 250 research projects in 13 developing countries over the past 20 years. This program has led into something that is now with us in the new Act, P.L. 95-602, with dollar support not only with developing countries, but also with the developed or industrialized countries.

The planning for the Long-Range Plan took all of this history into consideration. We recognized from whence we came, where we have been, and what the present status is. Recognizing that the P.L. 480 program as such is winding down and funds in most of these countries are not available anymore, we are looking naturally in other directions for dollar support to make this a more realistic approach for cooperative, collaborative efforts which join forces within other countries, and within the United States.

With the help and support of Mr. Joe LaRocca, serving as a consultant, our approach to this plan had a forward thrust by inviting in 60 or 70 individuals from four or five different sectors, talking to as many people as we possibly could, not just state/regional/federal, but other non-government agencies, all the way to the United Nations, the International Labor Organization, and the World Health Organization. We were trying to "tease out" what it is that we should be concerned with on the international scene as we make our plans for the next five years, and there has been a remarkable kind of response.

In terms of the scope of the Institute's International Program, this is what we feel should be the direction of the program for the future:

- Conducting an international rehabilitation, research, and demonstration program to develop new rehabilitation knowledge and methods
- Conducting a program for the exchange of experts in the field of rehabilitation and related activities with other nations as a means of increasing the skills of rehabilitation personnel
- Conducting, with the cooperating countries, a program for the training of their rehabilitation personnel in the United States and for the training of personnel in cooperating countries
- Conducting a program for the collection, translation, publication, and dissemination of international programs, research information of significant interest, and the exchange of practitioners and researchers in the United States and abroad
- Providing and enhancing technical assistance to and with other international agencies and organizations and other rehabilitation services and the services of other programs as they relate to handicapped people in the United States
- Providing fellowships to procure the assistance of highly qualified research fellows within foreign countries
- Providing for representation of the United States in the World Health Organization, the International Labor Organization, the

United Nations and other special programs, the Pan-American Health Organization, etc.

• Preparing position papers on rehabilitation for use by the Department of State and the official delegations to conferences conducted by the United Nations and specialized agencies

Next we developed six or eight principles governing administration of this International Program. Among these it was stressed that this program must tie in with and be an integral part of the domestic program. Also, it must have financing, not only by our government, but through shared responsibility with other governments. For instance, the U.S. is getting a tremendous number of appeals from interest groups from Japan and the Gulf area. Saudi Arabia was represented here this week with two or three other groups and will be coming back in the very near future. Exchanges are under consideration with the Latin American countries now, and China is certainly on the horizon. Now is the time when we must "move out." Perhaps at one stage of the program with some of the developing countries this exchange was a one-way street. But now nearly every one of the R&T Centers has been involved internationally in one way or another. If you are not going out at this time, certainly you are receiving the scientists as they come this way. The RTCs have done an excellent job and are appreciated and thanked for their support.

We are right at the verge of moving out into something very meaningful because in the new legislation Congress was impressed enough with the Special Foreign Currency Program, using U.S. owned dollars in the thirteen developing countries, to come through and set aside or at least indicate that dollars could now be used. There are eight projects now underway, small grants for the most part, but at least there is a thrust. These dollars are not for the most part going overseas; they are given to local agencies who are involved with projects in the areas of research, training, technical assistance, exchange of information, and exchange of experts. But the direction is there and we are just scratching the surface in terms of need and what can be done.

I could not help but notice in the INFORMER network display the fact that the map of the world is there before us with flags denoting the INFORMER's broad international circulation. You do not have to pick up December's issue of "Exchanging Research Internationally," but look at any one of your issues and you will find some international involvement. Perhaps this is another house organ, another direction in which we should be going to better tell our story in a more meaningful and significant way. So I commend the **INFORMER** and its publishers. I commend the organization of the National Association of R&T Centers for what has been happening in the past. We can use you and your expertise. Some 300 visitors visited with us in the last several years, and what do they want to see? Usually they want to see at least two or three R&T Centers on each visit. So the word is already out there, your Centers are on the map. We do not have to have a thrust or a formal program to present that. Your work is already being passed on to those in the field.

We are still just in the planning stage, but we hope and we think that this program really has something going, something very meaningful. With your help and assistance we can do much in terms of making this a meaningful program. With the 1980 International Year for Disabled Persons we would like to be "on the map" both here and abroad, stating that we have some very real contribution to make.

# New Directions for the RTCs

**Joseph Fenton, Ed.D.**
**Special Assistant to the Director, NIHR**

It is always a pleasure to have an opportunity to present an updating of where we, as RT Centers, have been during "the year that has been" and where it looks like we are going during the year ahead. Let me first state that one of the most significant "happenings" of the past year has been the appointment of the first Director of the National Institute of Handicapped Research, Dr. Margaret J. Giannini, and under her leadership the development of the Long Range Plan for the Institute. In that regard, I am pleased that we have had the opportunity this morning to hear a discussion of various aspects of the NIHR program plan from key NIHR staff who have had the opportunity to provide leadership in the development of the Plan. These presentations were purposely placed on the agenda by the Program Planning Committee to enable us to gain an appreciation of the total NIHR program plan and better conceptualize how the RTCs, which is surely the largest program within NIHR, can continue to be an integral part of the "whole." I am further pleased to note that as in the past, participants at the annual meeting include those from the federal and regional RSA offices, state and community rehabilitation agencies, consumers, RTC advisory committee members, and other grantees such as the RRRIs.

Please note our Special Centers Information Exchange Program display in the rear of the room. As it rotates around and around, the masthead reads "getting around for NIHR" and appropriately reflects the nature of the state-of-the-art and the movements and changes that have taken place in the past several years. However, while there have been many reorganizations and disorganizations almost annually within a variety of HEW, SRS, OHD, and RSA structures, changes within administration, department Secretaries, Assistant Secretaries, Commissioners, acting Directors, etc., the RTC Program has been able not only to survive but also grow, thrive and prosper throughout this period. This can only be attributed to our being able to work together to build a meaningful program of research and training which has consistently impacted on the practice of rehabilitation personnel, rehabilitation methods, and rehabilitation service systems. As a result thousands of handicapped persons have been help-

ed to achieve their own maximum state of independence and productivity.

What are the new directions for RTCs? Where have we been this past year and where are we going this next year? As you know, two Centers are being phased out as of June 30 and plans are underway to establish four new RT Centers by October 1, as follows: a new RTC in deafness, one on rehabilitation of aged handicapped persons to be funded collaboratively with the Center for the Studies of Mental Health of the Aging in NIMH, a center for independent living rehabilitation working closely with RSA, and a second RT Center in mental health rehabilitation also jointly funded by NIMH.

This past year we have completed the first phase of a study to determine the feasibility of an RT Center for the rehabilitation of handicapped Native Americans. This was initiated cooperatively through the University of Colorado RT Center with the Indian Health Services under contract with the Native American Research Firm. The first phase identified the needs and the complexities that exist in developing a workable service system for Native American Indians. The study clearly indicated that Native Americans recognize the problems and support the need for an RT Center. Further exploration is, however, necessary to determine how to put an RT Center into place which will be helpful to over 100 Native American tribes in the United States, each with individual cultures, and many with a desire for independent programs. The second phase of the study was created to determine how the Bureau of Indian Affairs, the Administration on Native Americans, and the Rehabilitation Services Administration programs can be integrated into an NIHR/IHS R&T Center effort. Hopefully, this second phase of the study will lead to a coordinated plan for a Research and Training Center for the handicapped Native Americans that will be established in FY 81.

The new thrust in the year ahead is not only the establishment of new RT Centers to meet new legislative mandates, but also increased interagency cooperation and participation of all of our efforts. We need to increase our knowledge about other federal agencies that have related program responsibilities in working with disabled persons. Yet interagency collaboration is not new to the RT Center programs. Many such efforts have already resulted in more fruitful program developments and fiscal support. As an example, the George Washington University R&T Center received a grant for $410,000 from the Department of Transportation to study and evaluate the District of Columbia's busses specifically designed for easy accessibility to handicapped persons. This grant included the development of a training package for bus drivers and bus supervisors whereby they may gain a better understanding of handicapped individuals and develop a positive attitude which will encourage the utilization of bus transportation.

The Office of Personnel Management (the former U.S. Civil Service) is working with us in a study of positions in the Civil Services to determine which are occupied by severely handicapped persons, the extent of success experienced by these persons, and adaptations necessary for success in these positions. The ultimate objective is to determine whether it is necessary to change job descriptions to enable more handicapped persons to have access to a greater number of federal work positions. The potential impact for increasing job opportunities in federal positions is far-reaching, and hopefully various RT Centers will become involved in this study through their regional civil service systems.

Another opportunity emanating from the President's Office in which the RT Centers can and should become involved and contribute substantially to is the Black College Initiative. There are over 100 historical black colleges throughout the United States which can benefit from technical assistance in developing a capacity to better obtain federal, state and local research and training grants. A number of RT Centers have and are working with the black colleges by establishing exchange programs, internships and fellowships. We wish to encourage creativity on the part of the RT Centers in developing helpful, supportive relationships with these colleges.

The three vocational rehabilitation R&T Centers have continued their leadership role in conducting the Institute on Rehabilitation Issues (IRI) program. For several years each of these Centers has, in cooperation with the state vocational rehabilitation agencies, identified VR training issues and needs which are selected annually by state agency personnel. The vocational RTCs provide the lead in working with VR to develop training publications and packages which are widely distributed and utilized by all vocational rehabilitation agencies. Surely we should consider extending this successful model to other rehabilitation areas of study utilizing other types of RT Centers. As an example, the mental retardation R&T Centers can develop a process for identifying three mental retardation or developmental disabilities issues annually and duplicate the model by developing training packages in these areas.

The new legislation has broadened the research mandate to include infants, children, youth, adults, and the elderly. The legislation now authorizes Centers to extend their responsibilities or to change core areas to include these new challenges.

Unique activities have resulted from supplemental funding to R&T Centers this past year. Many have had national and international impact. As an example, the Texas Tech Center participated in the International Year of the Child Program in cooperation with the National Association of Retarded Citizens and the International League for Retarded by sponsoring an international seminar in Puerto Rico which included Caribbean representatives in a program entitled "Retarded Child of Today, The Adult of Tomorrow." As we plan for the International Year of the Disabled, we will look forward to RTCs participation and development of creative ideas.

Also during this past year the University of Wisconsin Mental Retardation Center, in collaboration with the University of Oregon Mental Retardation Center, organized a program in which graduate students were partially sponsored in an international program of seminars in Egypt and Israel. They also participated in the International Conference on the Scientific Study of Mental Deficiency held in Israel. This effort resulted in an international exchange of information and knowledge and mutual appreciation of programs offered by the various countries involved.

The Special Centers Office and the National Association of R&T Centers need to continue cooperative relationships with the Executive Committee of that Association and with its Research and Training Committees. Hopefully, during the next year we will be able to continue our efforts with the Association's Evaluation Committee to reduce reporting procedures and implement the task force committee's recommendations without reducing RT Center accountability.

As an Institute, we must now reestablish

our relationship with the state vocational rehabilitation agencies and the RSA regional offices. We also need to maintain the strength of the RT Center Advisory Council relationship. This system is time-proven and serves as an excellent resource and asset to the program. The continued participation of consumers and relationships with consumer organizations on RT Center Advisory Councils is a significant aspect of the program which should be strengthened. I am proud to state that the value of consumer participation in RT Center program development and participation on Advisory Councils was recognized before it became "fashionable." The valuable contributions that handicapped persons have made in identifying research and training needs, service delivery problems and concerns with rehabilitation methods and services have contributed measurably to program planning and development.

A number of questions must be resolved during the coming year. How are we to increase the base grants of the newer and lesser funded RT Centers which have been productive and have the capacity to grow in a system where they will have to compete with the resources of the "biggies" on a competitive basis? What does the legislation really mean by authorizing "basic research?" What is really meant by "basic" research? Are we talking about competing with the National Institute of Health and other national institutes whose funding is one-hundredfold over and beyond the funds available to NIHR. Care is needed not to encourage the use of NIHR research funds for activities which are the responsibility of other agencies. We must also be sure that NIHR basic research does not become the "dumping ground" for research that has been turned down by other institutes making this an institute for funding research which can't "pass muster" by other agencies.

"Prevention" is also noted in NIHR's legislation. We need clarification on what Congress had in mind when the prevention mandate was included. Are we to be concerned with preventing cancer, arthritis, end stage renal diseases, stroke, myocardial infarctions, and other serious diseases? Are the NIHR's limited resources to compete with the NIH's prevention mandate of the Heart Institute, Cancer Center, Eye Institute, etc?

Of great significance, in a positive sense, is the newly established Office of the Assistant Secretary for Special Education and Rehabilitative Services. This office will provide the leadership and opportunities for collaborative program development for children, adults and the aged in education, habilitation, and rehabilitation research.

A word about our Information Exchange Program, the program launched several years ago to implement our mandate to disseminate new knowledge resulting from research findings, is appropriate at this time. I wish to acknowledge the fine continuing efforts and express appreciation for our close cooperation and working relationship with the Arkansas RT Center—with Vernon Glenn, Neal Little, and especially with Susan and David Sigman with whom I work on a day-to-day basis in the development and implementation of the various Information Exchange products such as the annual **Research Directory of the Rehabilitation Research and Training Centers,** the directory of RT Center publications and audiovisual aids, and particularly the **INFORMER.** I keep telling Susan that each issue is better than the last one and that I don't know how we're going to achieve a better one the next time; yet, somehow a rabbit is pulled out of a hat and the publication is always better. But the formula is not really one of magic. It is one of constant review and evaluation. As an example, six months ago we asked several information experts to offer suggestions and recommendations regarding the format of the **INFORMER.** As a result we now have a new format which highlights research and training activities under major topical areas as well as acknowledging the Centers responsible for each of the activities. Also, the RTC Training Calendar now appears in a separate section which can be detached and circulated to all staff. This change came about upon learning from state agency line staff that some agency administrative offices were receiving copies of the **INFORMER** but were not circulating them to all staff. Now the Training Calendar is designed so that it can be detached easily and circulated. In addition, each state vocational rehabilitation agency is now receiving up to fifty additional copies which can be forwarded to line staff.

We will also continue to publish the Research Directory for FY 1980 which will appear shortly after the end of the fiscal year and will enable everyone to keep up-to-date on all current and proposed RT Center research. This directory serves not only to disseminate and aid in the utilization of research findings, but also to encourage collaborative efforts and avoid unnecessary duplication.

We have also arranged for the Information Exchange Program to assume responsibility for the proceedings of each annual RT Center meeting, thereby assuring timely reporting and early distribution. We further perceive the extension of the Information Exchange Program to include more comprehensive coverage and dissemination of all of the NIHR's research related activities.

RT Centers continue to be an outstanding mechanism for resolving research issues and training needs of rehabilitation related agencies. There is hardly a meeting one attends on the federal, regional or state level where the RT Centers are not referred to as a resource for problem solving in research and training areas. The visibility, reputation and credibility the RT Centers have achieved over these past number of years speak well of the program. It is very important that the Centers continue to reflect such achievements in their annual reports and show the impact of the research and the training conducted in a manner which clearly demonstrates what the RTCs are doing and how the lives of handicapped persons are being impacted. We must continue to document how rehabilitation related curriculum in our universities have been enhanced and how the skills of rehabilitation practitioners have been improved through training seminars, conferences and publications produced by the RT Centers. We need to continually demonstrate how the investment in rehabilitation has reduced health care costs and tax burdens. As budgeteers look to see where reductions can be made, we must be cognizant that this type of reporting can help not only to maintain our program, but, hopefully, to increase its capacity.

We can anticipate that the year ahead will be another with many changes and opportunities for innovations. There is no question in my mind that the Centers can live up to these challenges and continue to be productive and contribute substantially to all aspects of rehabilitation knowledge in ways never before realized.

# Group Meeting Reports

## RTC Directors' Report

**Joseph B. Moriarty, Ph.D., Moderator**

The RTC Directors' group basically addressed three things. First was the issue of funding. Just for maintenance of effort purposes, increases in the 12-15 percent range are essential. What's more, the legislative mandate establishing NIHR contains an ambitious set of new initiatives for NIHR and the R&T Centers. We feel a little bit like the quote about being asked to do more and more with less and less so that soon we'll be able to do everything with nothing.

Secondly, there was considerable conversation at both today's meeting and at the Executive Committee meeting yesterday concerning the need for ongoing dialogue between R&T Centers and NIHR. A proposal is being formulated which would entail a representative group, perhaps a subcommittee of the Executive Committee, to meet regularly with Dr. Giannini and her staff to review current programs' progress being made in achieving program goals, obstacles to progress and the like.

The third major item which RTC directors addressed is the matter of getting necessary funds to support the Association of Rehabilitation Research and Training Centers. Institutional and individual dues were considered among other things, and it was agreed that this issue needs further attention.

## RTC Researchers' Report

**Marcus J. Fuhrer, Ph.D., Moderator**

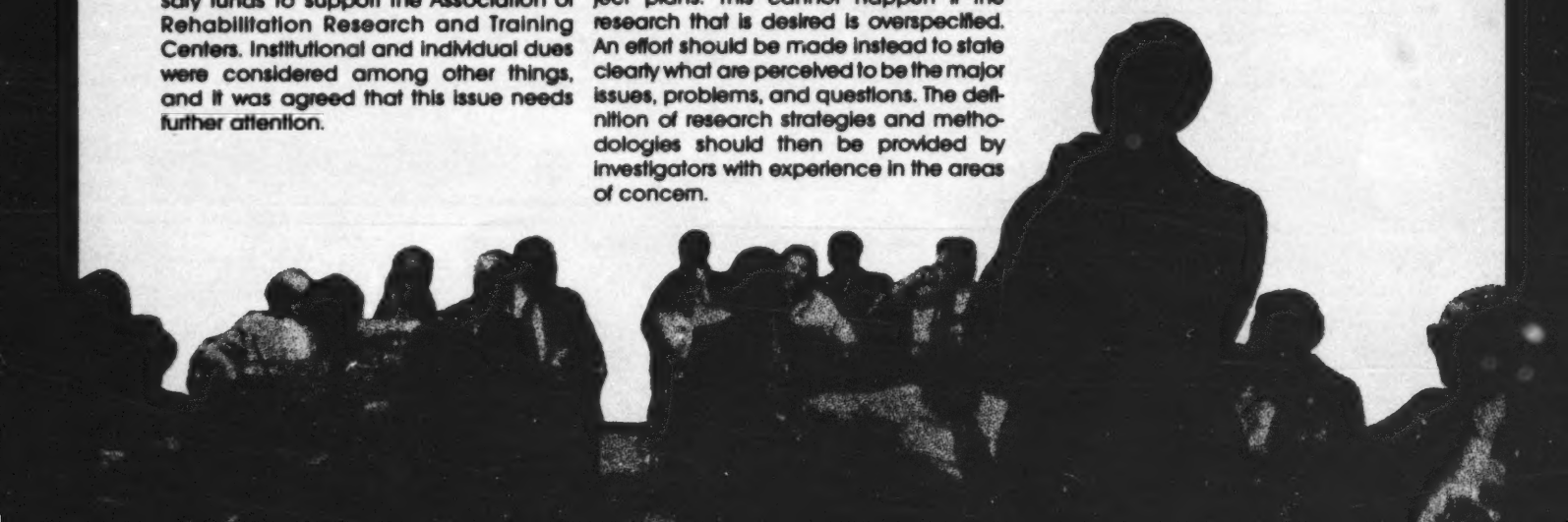
The Research Committee was struck with the recognition that long-range research planning requires appropriate time, resources, and sustained effort. Too often in the past, planning has been designed to start from "ground zero" rather than being conducted as a cumulative, evolutionary process. We believe that subsequent years' efforts should be devoted to elaborating, refining, and making operational the promising start that has been made this year. There should be systematic interaction of agency planners with this country's rehabilitation researchers—those in the RTCs and those working elsewhere. This interactive process should include regular colloquia or planning conferences that focus on discrete high priority problem areas and that have structured agendas and predetermined products (e.g., position papers, budget estimates).

It is crucial that the creativity and expertise of experienced investigators are exploited in moving through the planning process from the specification of needs to the formulation of specific research project plans. This cannot happen if the research that is desired is overspecified. An effort should be made instead to state clearly what are perceived to be the major issues, problems, and questions. The definition of research strategies and methodologies should then be provided by investigators with experience in the areas of concern.

We also wish to emphasize that it is important in the planning process that the Institute be as systematic in cataloging completed and ongoing research as it is in identifying areas requiring new efforts.

In our discussions, we noted a number of problems in the distinction between "applied" and "basic" research that is offered in the draft version of the proposed regulations. We made some progress in distinguishing these terms more adequately, but did not complete the task. We encourage the Association's members to consider carefully how these concepts are treated in the proposed regulations once they are published and recommendations for revisions are requested.

*Participants had the opportunity to discuss the NIHR Long Range Plan and other areas of mutual interest in four selected groups: RTC Directors, RTC Research, RTC Training, or Advisory Council/State/Federal Representatives and Consumers.*



## RTC Trainers' Report

**Donald W. Dew, Ed.D., Moderator**

The RTC trainers established five subcommittees during the past year. These subcommittees were organized to ensure organizational communication, collaboration and cooperation with an emphasis on working closely within the NARRTC, NIHR and RSA. Reports from each of the five subcommittees were as follows.

**1. Organizational Communication and Cooperation**

Linkages have been established with the Training Committees, the Council of State Administrators of Vocational Rehabilitation, the National Council on Rehabilitation Education, the Regional Rehabilitation Continuing Education Program and the Regional Rehabilitation Research Institute. The purpose of our contacts was to ensure that trainers within the RTC's were up-to-date with the current issues affecting training organizations associated with RSA and NIHR.

**3. Certification of Training**

The RTC trainers are quite concerned with the number of organizations which require certification for their training programs. At present, by individually having to certify trainees for numerous organizations, a great deal of trainers' time is being utilized by filling out certification forms and communicating with numerous organizations. It is felt that some progress has been made in standardizing some of the certification requirements of our respective trainees.

**3. Allocation of Training Monies**

This subcommittee was charged with determining how RTC's allocate training monies. Although Centers may handle funding differently, understanding the process may be helpful to the trainers at large.

**4. Improving Present Reporting Activities**

The present method of reporting training activities, it is felt, could stand improvement. Therefore, this committee is charged with exploring each individual center's reporting process, ultimately putting them together to help develop some clear recommendations which may benefit RTC trainers.

**5. Training Program Evaluations**

We have been concerned for some time with the current methods of evaluating training programs. It was hoped that this committee would make recommendations related to better methods of evaluating our training.

It was felt by the trainers that the abovementioned five areas require ongoing attention, and we will need to continue to work on these areas during the coming year.

The Committee discussed the NIHR long-range plan as related to training which was submitted by the Training Committee. As a result of this discussion, several recommendations concerning additional areas were made. They included ensuring that we had consumer involvement in training, and the effective use of telecommunications as a means of transferring information.

Finally, the trainers nominated seven individuals to serve on the Training Committee for the coming year. These nominations will be forwarded to Dr. John Goldschmidt, President of NARRTC for his consideration and, hopefully, appointment. They were as follows: Dr. Jean Cole, Baylor Medical Center; Dr. Bob Means, Arkansas Vocational Center; Dr. Donald Dew, George Washington University Medical Center; Dr. Darrell Coffey, University of Wisconsin-Stout Vocational Center; Dr. Mikal Cohen, Boston University Mental Health Center; Dr. Don Olson, Rehabilitation Institute of Chicago Medical Center; and Mr. Roger Decker, Emory University Medical Center. The committee also recommended that Mr. Decker serve as committee chairperson for the coming year.

**BELOW: Research faculty convene in workshop session.**

# Advisory Council, State/Federal Representatives and Consumers' Report

**Ralph N. Pacinelli, Ph.D., Moderator**

Some 35 individuals convened to discuss the assigned topic of the role and function of the RTC advisory council and the interaction of at least three classes of members on the council: state agency and federal representatives and consumers. The group was composed of state rehabilitation agency directors, advisory council members, consumers, RTC administrative staff, RSA Central and Regional Office staff, and NIHR personnel.

The group spent considerable time discussing the definition of consumer and determining how appropriate consumers might be identified for council membership. It was suggested that the "consumer" be a disabled person who is not employed by the RTC or any agency employee connected to the traditional state-federal rehabilitation network. The group reaffirmed the definition developed at the First Annual RTC Meeting in Arkansas. In addition, it was felt that a goal of 20% consumer membership should be aggressively pursued for all RTC advisory councils. Because there was insufficient time to explore this topic in the detail desired, the group recommended that the Association continue in its efforts to define "consumer" participation and to develop guidance for the RTCs.

In discussing the RTC advisory council, the group concluded that a council is mutually beneficial for RTC administrative and professional staff, the State rehabilitation agencies and other agencies and organizations who participate in research and training activities, especially as they relate to severely handicapped individuals. The group emphasized that councils could benefit from: (a) **membership** according to the Fenton paradigm (guidance developed and distributed by Dr. Joseph Fenton, Special Assistant to the Director, NIHR), (b) **size** that is controllable and manageable, (c) **orientation** training for council members, and (d) **clearly** articulating their role as advisory rather than policy-making and decision-making.

With the establishment of the National Institute of Handicapped Research, and the transfer of the RSA research program to the Institute, the discussion on the role of federal and state VR personnel was perceived as important, if not critical. The maintenance of linkages between NIHR and RSA and the state VR agencies is pivotal to sound and relevant rehabilitation research and training. The group felt that there should not be diminution of effort on behalf of RSA and state agency staff as they relate to the work of the Institute. It was strongly encouraged that RSA and NIHR develop a formal working agreement that would define their respective roles in expanding and improving rehabilitation research, training and practice. The group suggested that the RTC Association could play an important catalytic role in bringing these organizations together and in fostering cooperation, coordination and communication.

The session closed with the group reviewing the proposed federal regulations as they pertain to NIHR, especially Research and Training Centers. Several sections provided encouragement and comfort toward the strengthening of advisory councils and the roles to be played by various agencies, organizations and individuals. For example, Subpart D, Section 1364b.30 describes selection criteria relative to applications that might compete successfully for a RTC grant. Points are awarded the applicant if proof of support is shown from state rehabilitation agencies, public and voluntary organizations and consumers. Also, points are awarded for a description of an advisory council to be used in the development and operation of the RTC. In Section 1364b.42, the purpose and role of an advisory council are defined. The discussion group felt that these basic regulatory guidelines could serve as the springboard for future action.

# Legislative Update

**Moderator - John W. Goldschmidt, M.D.**
**Associate Project Director**
**Northwestern University Medical R&T Center**
**President-Elect, NARRTC**

**Patria G. Forsythe**
**Staff Director**
**Subcommittee on the Handicapped**
**U.S. Senate**

*This session was designed to bring conference participants up-to-date on current and pertinent issues relating to federal legislation in rehabilitation. Informal discussion followed the presentations by Patria G. Forsythe and Richard Verville.*

**OPPOSITE PAGE: Patria G. Forsythe, Staff Director, Senate Subcommittee on the Handicapped, and Richard Verville, Attorney at Law.**

The greatest concern I have these days is funding. It is a problem which is with us all the time, but it is becoming more and more prominent with the zeal to balance the budget. You are here during a very good week because the meetings now in the Senate concern the decisions to be made affecting programs for the year 1981. Everyone is fighting for every dollar, and I have both a personal and professional opinion about that. My professional opinion is one which says, "Yes, we should balance the budget." My personal opinion is one which says, "Fine, but not with money for the handicapped."

As you know there is a new Assistant Secretary for Special Education and Rehabilitative Services, Edwin Martin. I have known Ed for a very long time. He has been well oriented to both the Federal government and research, plus he is a terrific administrator. As an in-house advocate he has always been a person who manages to help his programs survive. That is a distinct asset, particularly in this day and age.

The names for the National Council on the Handicapped, which were announced by the President on May 1, have come over to the Senate. Papers have been sent to Council members requesting appropriate information, and just as soon as all fourteen members have returned the requested information there will be a group nomination hearing.

Perhaps most of you are wondering what is going to happen to the Department of Education and how the National Institute and the research programs are going to fare. I think both will fare very well, but it is going to depend a lot upon the attention given by the constituency which your program serves. I think the research program in the National Institute of Handicapped Research has essentially gone unscathed. Yet in a crucial year like this you need to do all you can to help. You do not necessarily have to have a Senator from your home state on the Appropriations Committee to start some action. You can go to whomever your Senator is and ask him or her to talk to the Appropriations Committee about an increase for your program. This is a tactic of which most of you know, but perhaps need to be reminded. Just let me say that since this increase in funding was proposed by the Administration and the President, I would keep pursuing the members until I got it!

## Legislative Update

**Richard Verville, Attorney at Law**
**White, Fine and Verville**
**Washington, DC**

*Mr. Verville is Counsel for the American Congress of Rehabilitation Medicine and is this year's recipient of the coveted Gold Key Award from that organization.*

One of the things I can do for you is provide budget information about the National Institute. First of all, the President presented the original budget in January 1980 for the FY 1981 which begins October 1, 1980, and in that original budget the Institute, which is now functioning at a level of 31.5 million, went up in its projected budget for FY 1981 by 5.5 million to a budget request of 37 million. That represents a fairly substantial increase: almost 20 percent. The rehabilitation services budgets for the VR program went up by 36 million in the President's original request from a base that is already 817 million; that is clearly not even an inflationary factor.

Independent living went up in the President's original budget by three million (from 15 to 18), exactly 20 percent. The other programs in rehab stayed at about the same level as FY 1980 except for the training program which came down from 28.5 million to 25.5 million, a three million dollar reduction. This is not the training which is part of the Research and Training Centers; it is the separate training program. The program called Innovation and Expansion Grants for special services the states might want to experiment with, was zeroed out in the President's '81 budget.

So on the whole there were very, very few increases and there were some major decreases such as training and the Innovation and Expansion Grant Program. The only increases at all that were of any substance were in independent living and the NIHR (about 20 percent) which, compared to any of the other programs in the Department of Education budget, were pretty big increases in this day and age. Very few programs received 20 percent increases. For example, in the President's original 1981 budget NIHR went up by something like three percent. The highest increase was the Arthritis Institute which went up by maybe eight percent. So in terms of a commitment to programs as reflected in a budget, it was really quite positive for the NIHR, and I think this is a great tribute to Bill Spencer's early work on how to organize a budget and those tedious hours he spent lobbying people within the Administration to support the program.

In March 1980, the President revised his budget for FY 1981 and proposed a good number of recisions of budget authority for the present year. None of these recisions are in rehabilitation, but a lot are in the health area. So the budget authority changes for the current FY do not affect rehab at all. But the President did propose revising his projected budget for 1981 in the Department of Education with a reduction in the Institute's budget by two million, bringing it down to 35 million dollars instead of 37 million (a 10 percent instead of 20 percent increase).

In terms of how that budget breaks down, all I can tell you is what the Administration proposes formally to the Congress. The breakdown that was officially transmitted by the Department of Education dealing with the Institute's 37 million dollar budget was broken down this way: research and training centers would receive 17.3 million representing a 1.5 million dollar increase; engineering centers and engineering projects likewise received a 1.5 million dollar increase and would be funded at 9.1 million; other research projects would be funded at 6.4 million which likewise is a 1.5 million dollar increase; utilization and dissemination of research results would be funded in the Presidents' original 1981 budget at four million which is a one million dollar increase; and international support would be kept at the same level which is only $100,000. If you add up all those figures you get 37 million, and you can clearly see that the five million dollar increase that was proposed in the budget was almost equally divided among the four major budget lines: research and training centers, engineering centers and projects, research and demonstration projects, and utilization and dissemination. However, you do not have to be a very knowledgeable mathematician to figure out that if all the increases are roughly equal and the bases very different, the percentages will be different. The big percentage increase was obviously in the utilization and dissemination area, the next biggest was in research projects, the third largest was in engineering centers and projects, and the smallest was in R&T Centers (a 1.5 million dollar increase over a fifteen million dollar base is only 10 percent).

In the revised budget request, which now stands at 35 million—what was done to achieve the two million dollar reduction was to basically reduce each program by the same amount, about $550,000. The RT Centers revised budget for FY 1981 is 16.7 million, the engineering centers and projects is 8.6 million, research and demonstration projects is 5.8 million, utilization and dissemination is 3.6 million and

the international support stays at one hundred thousand. Obviously the R&D and the engineering funds can be support money that goes into R&T Centers. I have never actually seen a breakdown of how that works, but Centers obviously compete and get, I would imagine, a fairly substantial percentage of those projects.

The Congress has had hearings on the original 1981 budget. The revisions came out in late March and the hearings that had public witnesses took place right after the revisions downward so most of the public witnesses were able to comment on the reductions. Your Association was represented in testimony. The state directors, the Congress of Rehabilitation Medicine, NRA, the Academy of Physical Medicine and Rehabilitation, and a couple of other groups also testified. We had agreed to a 45 million dollar 1981 budget, but some said that at a minimum do not let the budget drop below the original 37 million dollar request, otherwise we cannot possibly get a new Institute, with all the charges that it has, off the ground. This, I think, is a fair statement. It is absurd to think that with a 10 to 15 percent inflation rate you could start much new with a 20 percent increase. It makes it more absurd when you realize that in 1969 the budget for rehab and research was 32 million dollars. So the purchasing power of the research programs is about 50 percent less than it was in 1969.

The appropriations committees are facing the desire and probably legally imposed responsibility of balancing the budget. It will be legally imposed because Congress sets a budget ceiling in its budget resolutions as required by the 1974 Budget and Impoundment Act. The budget ceiling and revenue estimates that the Budget Committees in the House and Senate have come out with now project a balanced budget for 1981. The balanced budget would probably have enough room in it for the President's estimated 1981 programs. I do not think there is really a problem here for the NIHR. The problems arise mainly in those programs that are multi-billion dollar programs, like many of the income support programs and some of the defense procurement programs.

But I do not think the Congress is going to be very willing to put large increases into the budget over what the President requested. For example, NIHR, which is always a favorite in Congress, suffered in the President's revised budget by a cutback of three percent, and I think it will be difficult to get the Congressional Appropriations Committees to go above the President's budget request as revised. NIHR will probably be lucky to get them to put the 37 million dollars that the President originally requested in January into the program. That will take a lot of work by people like you talking with your senators and congressmen, particularly those who are on the Appropriation Subcommittee which deals with the Department of Education's budget.

The training program, too, is really in danger if that program, which has suffered a reduction of 2 million dollars already (30.5 million FY 1979 to 28.5 in FY 1980), gets down to 25.5 as proposed for 1981. There has been a substantial reduction in a budget that has not had increases for probably ten years. Less and less of what there is goes into long-term training in the professional disciplines that supply people who provide rehabilitation services, and more goes into short-term training, continuing education and in-service training activities with the state VR agencies. I am not trying to denigrate those three areas, but they have now become close to thirty percent of the training budget, whereas ten years ago they were about five percent of it. The reason perhaps is that the state agencies used to be able to do the necessary training out of monies other than direct federal training grants because the financial world was easier then and there were other forms of support. But as things have gotten worse states have had to use federal training grants for some of those activities, and that further cuts into the training done in the long-term area for various disciplines. If you look at a ten year period with grants and dollars in what I call the health-related disciplines (medicine, nursing, PT, OT, speech, prosthetics, orthotics), the money has gone down from 13.5 million to 9.5, and the grants have gone down by 30 to 40 percent. If you look at it nationally, it has been a precipitous decline and that program needs a lot of support.

One thing I would like to remind you about is that the Rehabilitation Act itself expires next June 30, so FY 1982 is the last year for which programs are authorized under the Act. That means for FY 1983, which begins October 1982, there has to be a new rehabilitation act. Hearings will start next spring, so you need to be thinking about this.

I feel, as many of you know, there is a serious problem in being transferred to the Department of Education. I think the value of it, however, is twofold in that you have an assistant secretary-level person responsible for handicapped programs and essentially only for that. He is a person whom I have known for ten years and is extraordinarily able as an administrator and a politician. You also have added visibility, for there is a National Council which can serve to give the area some real autonomy.

Compared to some prior years the budget actually looks rather good for '81 even with the revisions. But I think that the politics and the bureaucratic practices that I have seen in the government over ten years are such that it is going to be difficult because the constituency that drives the Education Department is the National Education Association, the American Federation of Teachers and maybe thirdly, the universities. But even more, I think, the teachers unions are a factor. And the people running the Department at higher levels will basically think of their role as dealing with education, because that is essentially what it is. So you are a service program in that constellation and you therefore have some inherent obstacles, due to the thrust of the new Department, in selling to the Secretary and the Under-secretary, and her and his immediate staff the relevance of rehabilitation. Those are the people in the Education Department that really, in addition to the OMB, make the decisions about the program. And those people are all very education oriented. Some extraordinary strides have been made in bridging the gap between health and education in some areas, so there is some hope. But I think you must continue to make that issue very clear because there is going to be some difficulty in making the rehabilitation case in an Education Department despite the fact there is an assistant secretary level person, and he is a very good one. The rehabilitation groups have to make a real strong effort to keep congressional committees, the Secretary, the Under-secretary and staff, and anybody else in the Executive branch who deals with the Education Department educated to the fact that there are a couple of programs in that Department that are not education programs.

# NARRTC Membership Assembly Business Meeting

**May 7, 1980 - 10:30 a.m.**
**Washington, DC**

The meeting was opened by Dr. Joe Moriarty, President NARRTC, with determination that a quorum was present.

Minutes were accepted as written. Treasurer, Dr. Carmella Gonnella reported that NARRTC has received a total of $90.00 in contributions to date. Bank service charge has reduced current balance to $76.42. NARRTC needs to establish a Taxpayers I.D. Number. Report accepted as read.

**Old Business:**
No items of old business were presented.

**Elections:**
Dr. Marc Fuhrer, Judge of Elections, presented the Nominating Committee report: For President-Elect, Dr. Fred Fay, and for Vice-President, Dr. Hank Brammell. Report accepted. No nominations from floor and nominations closed. Moved that there be cast by the Secretary a unanimous vote of approval for candidates as nominated. Motion passed.

**Membership Committee:**
No report.

**Research Committee:**
Reported that they have presented an updated draft on R&T Center evaluation to the Executive Committee and Board. Will request a by-law change on composition of Research Committee under new business.

**Training Committee:**
No report.

**Legislative Committee:**
Indicated that much of this Committee's report was covered during conference by speakers. Believe that there is a possibility to increase budget from 35 to 37 million dollars, but this must be accomplished in active collaboration with allied organizations and must be actively pursued in the next two months.

**Program Committee:**
Thanks were expressed by the President and all members present for the outstanding work accomplished by the Program Committee in such a short time. It was an excellent conference and appreciation was expressed to all involved.

**Liaison Committee:**
No report.

**New Business:**
Places and times for future meetings.

Moved that future sites be: 1981, San Francisco (in May depending on room availability); 1982, Atlanta; 1983, Seattle.
Dues: Moved and passed to initiate an individual dues policy of $10.00 and that individual Centers voluntarily contribute an institutional assessment with the amount to be determined by them; that a projected budget be prepared; that exhibits be utilized to generate income; and that other resources such as registration fees for conferences also be explored.

**National Council on the Handicapped:**
The following persons will be Members of the National Council on the Handicapped for the terms indicated:

For a term of 1 year:
- Nelba R. Chavez of Arizona
- Nanette Fabray MacDougall of California
- John P. Hourihan of New Jersey
- Odessa Komer of Michigan
- Edwin O. Opheim of Minnesota

For a term of 2 years:
- Elizabeth Monroe Boggs of New Jersey
- Mary P. Chambers of New Hampshire
- Jack Genair Duncan of South Carolina
- Thomas Joe of the District of Columbia

For a term of 3 years:
- Donald E. Galvin of Michigan
- Judith E. Heumann of California
- Howard A. Rusk of New York
- J. David Webb of Georgia
- Henry Williams of New York

**By-Laws:**
The Research and Training Committee recommended that Article VIII, Section 5 of the By-laws be amended as follows:
First sentence should read:

"The Committee should consist of up to nine (old seven) members appointed by the President, following nomination of a slate of candidates by the Directors of Research/Training, in annual assembly."

Also, a new sentence to be added:

"No Center type should be represented in the majority."

Amendment accepted to be voted upon at next annual assembly in accord with Association by-laws.

Last item of business was passing of gavel to the incoming President, Dr. John Goldschmidt, who adjourned the meeting at 12 noon.

**Dan McAlees/Secretary**

**Photo: NARRTC incoming President, Dr. John Goldschmidt (right) presents plaque of appreciation to retiring President, Dr. Joseph Moriarty.**

## NARRTC Executive Committee Meeting

Joseph B. Moriarty, Ph.D.
President, NARRTC

Daniel C. McAlees, Ph.D.
Secretary, NARRTC

**May 4, 1980 - 4:00 p.m.**
**Washington, DC**

The meeting was opened by Dr. Joe Moriarty, President NARRTC, with official determination of quorum present and development of agenda. Items presented as agenda items were (1) mailgram from Dr. Margaret Giannini; (2) NIHR long-term planning; (3) congressional appropriations; (4) report of NARRTC Research Committee; (5) mechanics and content of Business Meeting, i.e., elections, future meeting sites for NARRTC conferences, by-law changes, dues, committee appointments, etc.

**Item : Mailgram from Dr. Giannini**

It was felt that the mailgram indicates that carry-over of monies for on-going program activities is acceptable, however, grant awards and comments of other NIHR officials to date do not appear to reflect this. Thus, there needs to be a clarification as to whether these carry-over monies are to be used for supporting on-going program activities or whether they must be applied to **new** initiatives. The Executive Committee goes on record that their interpretation and understanding is that carry-over monies can be used for the purpose of supporting **continuing** program activities and that the mailgram is clear on this issue. If the NARRTC officers find a differing interpretation during discussions with Dr. Giannini and other NIHR officials during the conference, they will so notify the membership.

The Executive Committee also discussed their interest in providing input to NIHR regarding such issues as how funds are distributed, how new initiatives are determined and implemented, establishment of new R&T Centers, etc. The Executive Committee felt it was critical to continually reinforce the center network concept and programmatic research vs project research.

It was moved and passed that the Executive Committee direct the President to request bi-monthly meetings with Dr. Giannini for the purpose of discussing issues such as the above.

General discussion that followed brought forth the following conclusions (1) there is a need to develop a paid NARRTC staff position to provide a **presence** in Washington; (2) there is a need to develop position (issue) papers and collate/combine existing NARRTC papers into an on-going comprehensive position statement (rationale) for the R&T network concept; (3) there is a

need to encourage the appointment of a NIHR Deputy Director who is knowledgeable and experienced in the R&T movement; (4) there is a need to create an archive of R&T papers, minutes, committee reports, etc. from the past which is kept current. Dan McAlees was requested to initiate this activity.

**Item II: NIHR Long-Range Planning**

Since the primary thrust of the conference was the NIHR Long-Range Plan, it was felt that extensive discussion was not appropriate at that time. It was noted that there have been very fine submissions to the plan from all aspects of the RTC network. The final organization and format of the plan are unknown at this time. A consultant has been employed by NIHR Special Centers Office to assist in the final preparation of all RTC input.

It was moved and passed that the NARRTC President advise Dr. Giannini that we request a separate R&T component in the NIHR plan that reflects the programmatic nature of R&T research.

**Item III: Appropriations**

Appropriations last year were 31.5 million. The President is currently requesting 35 million. Other groups (NRA, etc.) are supporting a 45 million request. We should work hard for no less than the 37 million originally requested. President Joe Moriarty discussed testimony he gave before Congress. This testimony is in writing for those who would like to review it. Finally, individual center directors will be assigned specific congressional representatives to visit while in Washington for the conference.

**Item IV: Report of Research Committee**

This is an update of the 1978 report of the Research Committee. The report was accepted by the Executive Committee and recommended for approval by the Board with the provision that any person who has comments will be able to present them to a scheduled meeting of the Research Committee during the conference. The Research Committee will make any changes it deems appropriate based on this input and the plan will then be passed on to NIHR via the President.

**Item V: Business Meeting**

It was determined that the mechanics of the Business Meeting regarding elections, committees, by-laws, meeting sites, etc. were prepared; thus, discussion focused on Association dues. In order to accomplish the goals of the NARRTC, monies have been and will need to be used for travel for testimony, correspondence, postage, stationery, secretarial assistance, phone, payment to legislative consultant, duplication, etc. The Executive Committee recommended to the Board of Governors that an individual dues policy be instituted by NARRTC in the amount of $10.00, as provided in the by-laws of the Association.

Meeting adjourned 7:30 p.m.

**Dan McAlees/Secretary**

## NARRTC Board of Governors Meeting

**May 5, 1980 - 5:00 p.m.**
**Washington, DC**

Meeting opened by Dr. Joe Moriarty, President, NARRTC. It was determined that a quorum was present. Minutes were approved as written. Treasurer, Dr. Carmella Gonnella reported that NARRTC has received a total of $90.00 in contributions from the Executive Committee in 1979. Current balance is $76.42. NARRTC needs to establish a Taxpayers I.D. Number. Treasurer's report approved as presented.

**Old Business:**

No items of old business were presented.

**New Business:**

Extensive discussion of the 1.2 million dollars being made available for new initiatives occurred. To be eligible for these monies a proposal must demonstrate a new initiative, not just maintenance or expansion of current activities. The need to ensure cooperation vs. competition was stressed in the efforts of the Centers to secure additional dollars.

Carry-over monies were discussed with the consensus that they could be utilized for continuing program activities and that all requests for carry-over monies should be accompanied by a sound rationale for utilization other than to offset inflation.

NIHR reimbursement of established university overhead rates was discussed with widely varying opinions expressed. President-Elect Dr. John Goldschmidt was requested to establish a committee to recommend a NARRTC position on reimbursement of established overhead rates for transmittal to NIHR.

Regarding dues, the Board recommends by motion to the NARRTC membership meeting that individual dues be established, at the rate of $10.00, and that voluntary institutional dues/fees/contributions be requested (dollar amount to be established by each individual Center) for the purpose of supporting the activities of the Association.

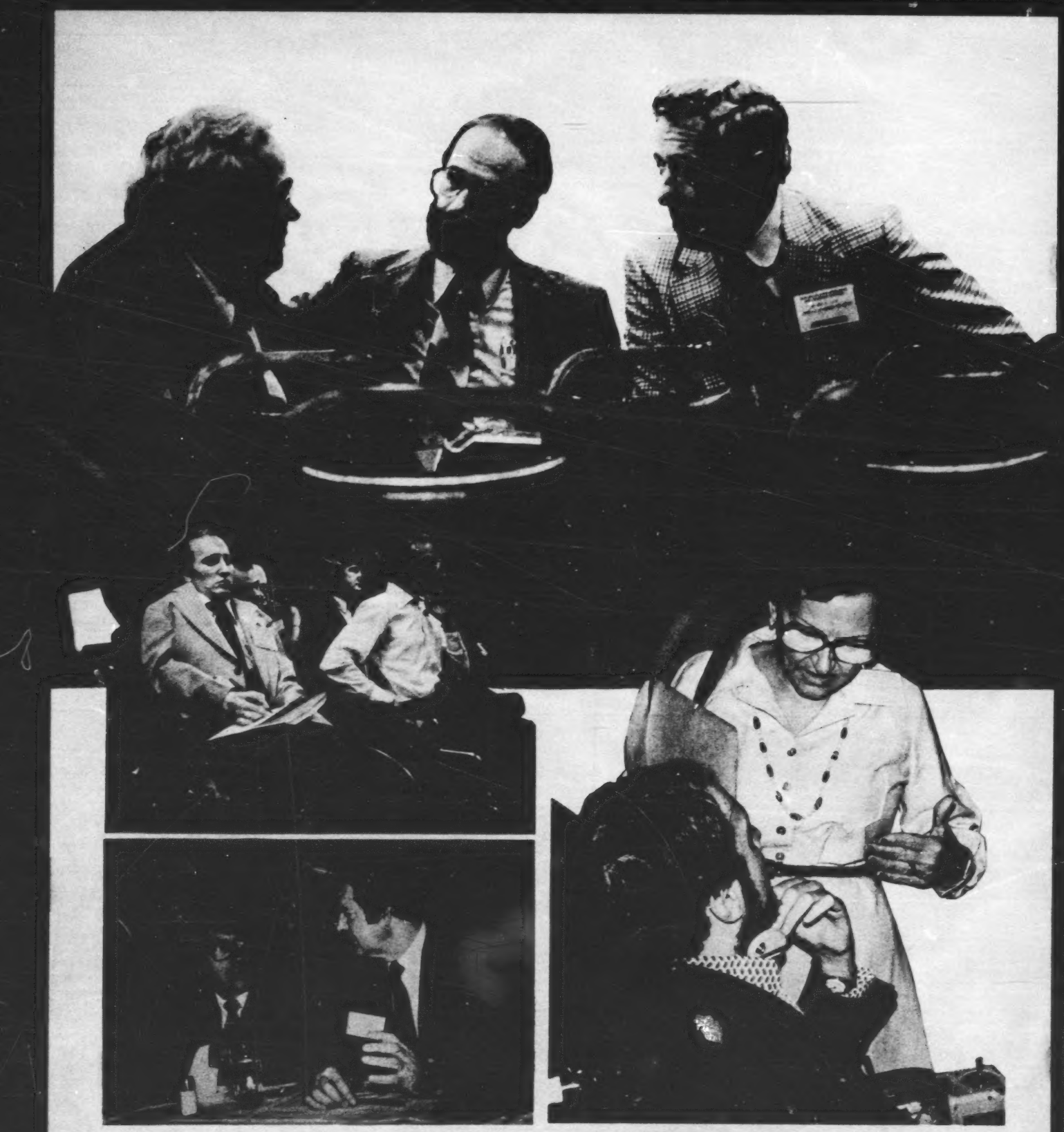
The Board also accepted by motion the recommendation of the Executive Committee to request bi-monthly meetings with Dr. Giannini for the purpose of providing NARRTC input to NIHR policy determinations. (It was recommended that the elected officers of NARRTC represent the Association at these meetings.)

Meeting adjourned 6:30 p.m.

**Dan McAlees/Secretary**

## Conference Highlights

**OPPOSITE PAGE: Vocalist Donna Eggert, husband Todd, and canine companions Vista and Alice delight banquet guests. TOP: (left to right) Honorable Jennings Randolph, Chairman, and Ms. Patria G. Forsythe, Staff Director, Subcommittee on the Handicapped, U.S. Senate; and Joseph Fenton, Ed.D., Special Assistant to the Director, NIHR. BOTTOM: The annual meeting presents an opportunity for informal interaction.**



TOP: (left to right) Drs. William A. Spencer, Project Director, and Marcus J. Fuhrer, Director of Research, Baylor College of Medicine R&T Center; and Dr. Neal D. Little, Associate Project Director, University of Arkansas R&T Center. CENTER: (foreground - left to right) John D. Collins and James Ellenburg participate in consumer workshop. BOTTOM LEFT: (left to right) Dr. Jorge C. Rios, Chairman, Department of Medicine, The George Washington University Medical Center, and Dr. John Goldschmidt, Associate Project Director, Northwestern University Medical R&T Center. BOTTOM RIGHT:Ms. Patria G. Forsythe and Dr. Fred Fay exchange views on federal legislation.



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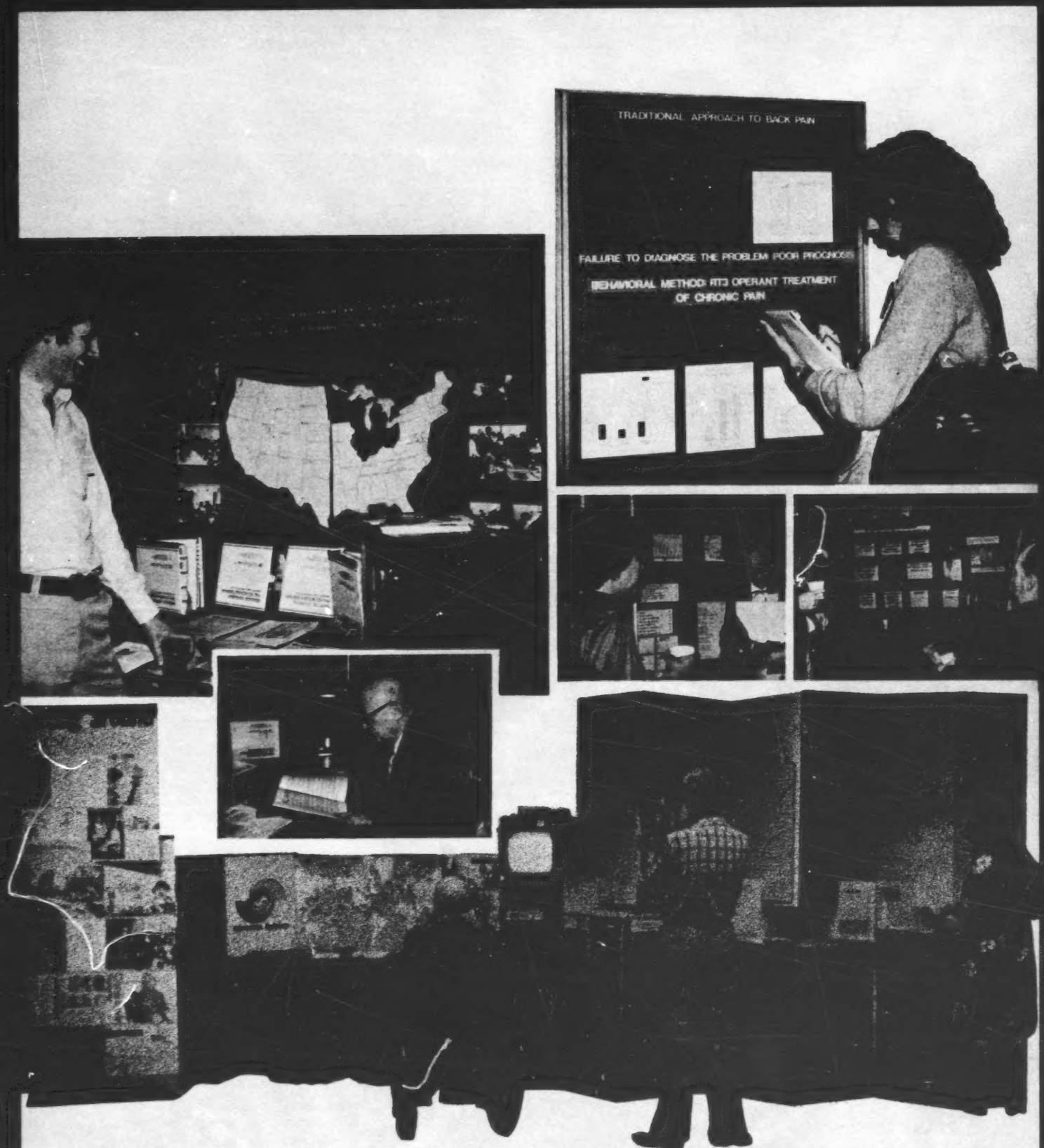
TRADITIONAL APPROACH TO BACK PAIN
FAILURE TO DIAGNOSE THE PROBLEM POOR PROGNOSIS
BEHAVIORAL METHOD: RTJ OPERANT TREATMENT
OF CHRONIC PAIN

**ABOVE: RT Center displays highlighted research and training activities from around the country in a variety of formats including print media and audiovisual productions. Conference participants had access to materials reflecting medical, vocational, mental retardation, deafness, mental health, and blindness rehabilitation projects throughout the 2½ day meeting. The National Rehabilitation Information Center (NARIC) from Catholic University, Washington, DC; REHAB BRIEF from the University of Florida (RRI), Gainesville; and the NIHR Information Exchange Program from the University of Arkansas (RTC); were also on display.**

# Conference Program Committee

**Irene Tamagna, M.D.**
**Project Director**
**The George Washington University Medical R&T Center**
**Chairperson, Conference Program Committee**

**Donald Dew, Ed.D.**
**Director of Training**
**The George Washington University Medical R&T Center**
**Coordinator, Conference Program Committee**

**Planning Committee members (L to R) Altamont Dickerson, Jr., Dr. LeRoy Spaniol, Dr. Don A. Olson, Dr. John M. Cobun, Dr. Joseph Fenton, Nancy Floyd (RT-9 secy.), Dr. Robert P. Jacobs, Dr. Donald W. Dew, and Dr. Irene Tamagna (facing group). Not shown: Dr. Ralph Pacinelli, Vernon Hawkins, and Liz Minton.**

## Program Committee

**Dr. Irene Tamagna,** Chairperson
Director
The George Washington University Medical R&T Center

**Dr. John Cobun**
Assistant State Superintendent
Division of Vocational Rehabilitation
Maryland

**Dr. Donald W. Dew**
Director
Training and Research Utilization
The George Washington University Medical R&T Center

**Altamont Dickerson, Jr.**
Commissioner
Department of Rehabilitative Services
Virginia

**Dr. Joseph Fenton**
Special Assistant to the Director
National Institute of Handicapped Research

**Vernon Hawkins**
Acting Chief
Bureau of Rehabilitation Services
District of Columbia

**Dr. Robert P. Jacobs**
Director of Research
The George Washington University Medical R&T Center

**Elizabeth B. Minton**
Director of Training
West Virginia University Vocational R&T Center

**Dr. Don A. Olson**
Director of Education and Training
Rehabilitation Institute of Chicago
Northwestern University Medical R&T Center

**Dr. Ralph N. Pacinelli**
Regional Director
RSA/OHDS, Region III

**Dr. LeRoy Spaniol**
Director of Research
Boston University Mental Health R&T Center

# Conference Participants

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**Arlene Asigan**
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**Dr. Lee Coleman**
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Washington, DC

**John D. Collins, III**
Consumer Representative
Alexandria, Virginia

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**Paul J. Corcoran, M.D.**
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**Nancy Downes**
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**Jack Duncan**
National Rehabilitation Association
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**James Ellenburg**
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Birmingham, Alabama

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**Tim Flannigan**
College City, Maryland

**Wilbert E. Fordyce, Ph.D.**
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Northwestern University R&T Center
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**Sandra Gonzalez**
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# Evaluation
# NARRTC Fourth Annual Conference

**Dr. Irene G. Tamagna, Program Chairman**
**Dr. Donald W. Dew, Program Coordinator**

At the conclusion of the 1980 NARRTC/RTC Conference in Washington, DC, registered participants were mailed a one-page questionnaire asking for their evaluation of the conference and recommendations for future conferences. The host center received an approximate 20% response to the questionnaire. The following is a brief summary designed to offer suggestions for planning of the 1981 NARRTC/RTC conference.

**Please indicate the most productive aspect of the conference.**
The respondents seemed basically in agreement concerning this first question and rated the opportunity to meet with Dr. Giannini and hear her discuss plans for NIHR's future, to discuss the new NIHR regulations, and the five-year NIHR plan as highest. In addition, the opportunity to meet with other R&T Centers' personnel was listed as a most productive aspect.

**Please indicate aspects of the conference which you would have changed or omitted.**
This question solicited a few different thoughts. Some individuals felt that there was too much structured time and meals as well as too many separate workshops. Other individuals felt that more time should have been allotted for the host center to present its research and training activities. Some participants suggested that presentations from R&T Centers' researchers and trainers involved in specific projects should have been presented to the entire group.

**Please indicate topics or issues for next year's conference.**
Several individuals indicated interest in a follow-up of the five-year NIHR plan as well as an update on the organizational and administrative structure of NIHR. There were comments suggesting more involvement with the advisory council representatives, in particular, with the handicapped consumers.

**Other comments.**
One suggestion was to devote more time to intellectual pursuits. It is assumed by this comment that again research or specific training activities carried on at individual centers might be presented to the entire group. There was one comment suggesting that the exhibits be eliminated due to the expense of transporting them and the lack of interest.

Although the host center was somewhat disappointed in the response return of its evaluation survey, it is apparent that individuals felt the conference was productive, useful and an important activity for exchanging information and new ideas.